

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Public and patient involvement in child health research and service improvements - a survey of hospital doctors
AUTHORS	Winch, Rachel; McColgan, Martin; Sparrow, Emma; Modi, Neena; Greenough, Anne

VERSION 1 – REVIEW

REVIEWER	Reviewer name Miss Julie Menzies Institution and Country Nurse Researcher Paediatric Intensive Care Unit Birmingham Women's and Children's NHS Foundation Trust, Steelhouse Lane Birmingham B4 6NH Competing interests Nil
REVIEW RETURNED	09-Oct-2017

GENERAL COMMENTS	<p>Understanding barriers to conducting PPI is extremely important. This paper offers the perspective of RCPCH members on the type of support available locally, the challenges in undertaking PPI and the support members wanted from the RCPCH.</p> <p>It is encouraging to see this work taking place to highlight the importance of engaging with CYP and parents. There are clear recommendations for the future and it is clear the RCPCH has introduced a number of initiatives and guidance to help members in conducting meaningful PPI. My comments / observations are below (numbered only for ease of reference).</p> <p>1. Abstract: The main outcome measures listed in the abstract are the proportion of organisations which had PPI central to research and service improvements, however the survey reports on respondents, not the organisations to which they are affiliated. It is unclear how many organisations are represented within the survey and therefore I was uncertain if you can claim it is the proportion of organisations.</p> <p>2. Introduction section: the aim of the study is identified as 'to determine whether RCPCH members feel supported by their organisations to undertake PPI activity'. However, it does not make it clear that this is in relation to research and service improvement activity which is stated in the abstract.</p> <p>3. The benefits to involving CYP and parents in research design and service improvements are not specifically addressed within the introduction. For a reader wanting to understand more about why this is priority this would be beneficial. Similarly, with PPI now a requirement for REC submission and for funding applications I also wonder if it might be useful to highlight that PPI is regarded as a crucial aspect of research conduct, not just good practice?</p>
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	<p>4. Methods: for those outside of medicine it is not particularly clear what level of experience specialist and speciality (SAS) Doctors have</p> <p>5. The date the survey was distributed is unclear. Can you clarify when this was conducted. Were any reminders sent or were any other methods of encouragement employed?</p> <p>6. Response rates for the survey are reported but responses to some questions are not reported (see point 7 below). Unclear if this is because of missing responses / incomplete questionnaires? Or if respondents had no comment on particular questions.</p> <p>7. Development of the survey was unclear. In the contributor statement there is reference to the survey being developed from a 2011 survey but it is unclear how this or the subsequent survey were developed. Was there any PPI involvement within the survey development? Did piloting of the survey take place?</p> <p>8. Within the 'questions asked' section of the methods, there are questions missing which are listed in the supplemental material. The questions about 'in your experience what works well and why' and 'please share your examples of best practice in PPI' are not made reference to. These aspects are not referred to throughout the whole paper. Unsure if this is because respondents were not familiar with PPI, had no experience or whether they struggled with knowing what 'good' PPI looks like. Is it notable that only negative outcomes are reported?</p> <p>9. Results section: there are no demographic results about the participants, other than their level of qualification. The survey asks questions about how they feel about PPI and the support they have access to but doesn't identify what experience respondents have in conducting research and in conducting PPI.</p> <p>10. With multi-centre studies, the PPI work will have been conducted by the CI and their research team at one location. There will not have been PPI work by the local PI at the local site. Are respondents therefore truly aware of the extent of PPI work which is taking place in research? Uncertain how this might influence their perceptions of the importance of PPI in research within their organisation.</p> <p>11. Within the results section there is a lack of consistency in the use of numbers or written numbers eg 14.4% said.. Thirty-six percent said...</p> <p>12. The initial results are very descriptive. Would a simple figure help explain the data better and allow the authors to focus on the key messages within the text?</p> <p>13. In places percentages are reported without an indication of the total number of respondents. Could the authors report these as well.</p> <p>14. It would be interesting to know the number of respondents who provided additional free-text responses. In relation to the question about how the RCPCH can support the respondent in involving patients and public for example there are no response rates reported and there is no indication of the magnitude of opinion on each point listed.</p>
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	<p>15. Limitations are referred to within the discussion section but there is no specific section for this. Although the response rate may not be reflective of all membership, there are other limitations which could be acknowledged; including the lack of demographic data and the lack of information about respondent's exposure to and experience of conducting PPI.</p> <p>16. Discussion: much of the literature in the discussion refers to initiatives that have been implemented after 2015. As the date the survey was conducted is not explicit it is difficult to know what information / resources were available at the time of the survey. Might it have been useful to have contextualised the results with what was known / available at the time of the survey?</p> <p>17. If most of the work was conducted after the survey is it worth resurveying participants to review how their views have changed to assess the impact of all these measures? There is a big emphasis within the PPI literature on assessing the impact of PPI. Reporting members views on these initiatives / impact on their attitudes would be useful to capture.</p> <p>18. The results of this paper offer a fascinating insight into the attitudes of RCPCH members to PPI and the challenges researchers face. However, the discussion mostly features reference to guidance introduced, and is reported in a slightly list-like manner. I appreciate this is providing evidence of measures introduced by the RCPCH to address members concerns but I would have liked to see the results compared and contrasted with other research (where it exists) on undertaking PPI to understand more about the similarities / differences with other participant groups.</p> <p>19. Gamble C, Dudley L, Allam A, Bell P, Goodare H, Hanley B, et al.2014. Patient and public involvement in the early stages of clinical trial development: a systematic cohort investigation. BMJ Open. 2014;4:e005234 highlight decreasing PPI in paediatric research which might fit with the challenges you report.</p> <p>20. In the discussion section I struggled with the third paragraph about the role of the RCPCH is monitoring time for professional activities. Is this to provide insight into the challenge articulated by RCPCH members about a lack of dedicated time to engage in PPI? I think this needs to be directly related to your results as it seems a little disjointed to me.</p>
REVIEWER	<p>Reviewer name Rachel Agbeko</p> <p>Institution and Country The Great North Children's Hospital</p> <p>The Newcastle upon Tyne NHS Foundation Trust</p> <p>UK</p> <p>Competing interests none</p>
REVIEW RETURNED	19-Oct-2017
GENERAL COMMENTS	<p>The authors address an area of major importance, that is, the voice of the patient and their parents in the decision making, development and organisation of child health services and research.</p> <p>The data provided stems from a questionnaire sent to Consultant/SAS Paediatricians who are members of the RCPCH. The response rate is below the 70% cut off to be assured of representative sampling (<50%).</p>

	<p>The questionnaire has an element of leading questions (i.e. Patients and the public are involved in service improvement in my organisation, but it can be tokenistic). In the results section it would be interesting to read what the respondents themselves are doing or have tried and mention as what works well (if any data is available in that area). The discussion reads more like an advertisement for the resources the RCPCH offers in PPI and could be enhanced by a discussion of practice in other areas that have shown success, e.g. via the NIHR CRN. Childhood PPI might also be framed in societal terms, that is how the child/young person's voice is valued in the UK and how this may differ from other countries. This then might lead to different interventions. Other work such as the Horizon 2020 project on Models of Primary Healthcare for Children focuses on hearing from children directly in matters of autonomy, voice in treatment. There are several YPAG in the country, one of which is YPAG-NE which challenges the notion that running such a group requires much designated SPA time. In summary, the sample may not be representative of views and potentially not reflect what is actually happening with regards to PPI. The discussion could do with a wider context.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Understanding barriers to conducting PPI is extremely important. This paper offers the perspective of RCPCH members on the type of support available locally, the challenges in undertaking PPI and the support members wanted from the RCPCH. It is encouraging to see this work taking place to highlight the importance of engaging with CYP and parents. There are clear recommendations for the future and it is clear the RCPCH has introduced a number of initiatives and guidance to help members in conducting meaningful PPI.

RESPONSE: We thank the reviewer for the kind comments.

*1. Abstract: The main outcome measures listed in the abstract are the proportion of organisations which had PPI central to research and service improvements, however the survey reports on respondents, not the organisations to which they are affiliated. It is unclear how many organisations are represented within the survey and therefore I was uncertain if you can claim it is the proportion of organisations.

RESPONSE: We have changed the wording to clarify "The proportion of respondents who said that PPI central to research and service improvements in their organisation"

2. Introduction section: the aim of the study is identified as 'to determine whether RCPCH members feel supported by their organisations to undertake PPI activity'. However, it does not make it clear that this is in relation to research and service improvement activity which is stated in the abstract.

RESPONSE: We have now clarified this in the introduction.

3. The benefits to involving CYP and parents in research design and service improvements are not specifically addressed within the introduction. For a reader wanting to understand more about why this is priority this would be beneficial. Similarly, with PPI now a requirement for REC submission and for funding applications I also wonder if it might be useful to highlight that PPI is regarded as a crucial aspect of research conduct, not just good practice?

RESPONSE: We have now modified the introduction as suggested.

*4. Methods: for those outside of medicine it is not particularly clear what level of experience specialist and speciality (SAS) Doctors have

RESPONSE: This information has now been given in the methods.

*5. The date the survey was distributed is unclear. Can you clarify when this was conducted. Were any reminders sent or were any other methods of encouragement employed?

RESPONSE: This information has now been included in the methods.

*6. Response rates for the survey are reported but responses to some questions are not reported (see point 7 below). Unclear if this is because of missing responses / incomplete questionnaires? Or if respondents had no comment on particular questions.

RESPONSE: The denominators have now been given in the relevant results section to indicate the number responding to each PPI question.

*7. Development of the survey was unclear. In the contributor statement there is reference to the survey being developed from a 2011 survey but it is unclear how this or the subsequent survey were developed. Was there any PPI involvement within the survey development? Did piloting of the survey take place?

RESPONSE: The contributor statement has now been modified to further clarify how the survey was developed.

*8. Within the 'questions asked' section of the methods, there are questions missing which are listed in the supplemental material. The questions about 'in your experience what works well and why' and 'please share your examples of best practice in PPI' are not made reference to. These aspects are not referred to throughout the whole paper. Unsure if this is because respondents were not familiar with PPI, had no experience or whether they struggled with knowing what 'good' PPI looks like. Is it notable that only negative outcomes are reported?

RESPONSE: In the methods, we have now included what works well and why and please share your examples of best practice. We have now included in the results less than 30% gave any suggestions so we have not commented further.

*9. Results section: there are no demographic results about the participants, other than their level of qualification. The survey asks questions about how they feel about PPI and the support they have access to but doesn't identify what experience respondents have in conducting research and in conducting PPI.

RESPONSE: We did not ask them for their demographics other than their level of qualification. We have previously reported on their research experience and now cross-reference this.

10. With multi-centre studies, the PPI work will have been conducted by the CI and their research team at one location. There will not have been PPI work by the local PI at the local site. Are respondents therefore truly aware of the extent of PPI work which is taking place in research? Uncertain how this might influence their perceptions of the importance of PPI in research within their organisation.

RESPONSE: We have now commented on this in the discussion; our survey was focused on the local organisation.

11. Within the results section there is a lack of consistency in the use of numbers or written numbers eg 14.4% said. Thirty-six percent said...

RESPONSE: Our understanding is it is not appropriate to start a sentence with a number, but if a number is greater than ten in the text it is reported as a number.

*12. The initial results are very descriptive. Would a simple figure help explain the data better and allow the authors to focus on the key messages within the text?

RESPONSE: We have now added a figure.

*13. In places percentages are reported without an indication of the total number of respondents. Could the authors report these as well.

RESPONSE: This has now been done.

*14. It would be interesting to know the number of respondents who provided additional free-text responses. In relation to the question about how the RCPCH can support the respondent in involving patients and public for example there are no response rates reported and there is no indication of the magnitude of opinion on each point listed.

RESPONSE: This has now been provided.

15. Limitations are referred to within the discussion section but there is no specific section for this. Although the response rate may not be reflective of all membership, there are other limitations which could be acknowledged; including the lack of demographic data and the lack of information about respondent's exposure to and experience of conducting PPI.

RESPONSE: We have now added these limitations.

16. Discussion: much of the literature in the discussion refers to initiatives that have been implemented after 2015. As the date the survey was conducted is not explicit it is difficult to know what information / resources were available at the time of the survey. Might it have been useful to have contextualised the results with what was known / available at the time of the survey?

RESPONSE: We have now included further discussion on this.

17. If most of the work was conducted after the survey is it worth resurveying participants to review how their views have changed to assess the impact of all these measures? There is a big emphasis within the PPI literature on assessing the impact of PPI. Reporting members views on these initiatives / impact on their attitudes would be useful to capture.

RESPONSE: We intend to undertake such a survey.

18. The results of this paper offer a fascinating insight into the attitudes of RCPCH members to PPI and the challenges researchers face. However, the discussion mostly features reference to guidance introduced, and is reported in a slightly list-like manner. I appreciate this is providing evidence of measures introduced by the RCPCH to address members concerns but I would have liked to see the results compared and contrasted with other research (where it exists) on undertaking PPI to understand more about the similarities / differences with other participant groups.

RESPONSE: We have now done this.

19. Gamble C, Dudley L, Allam A, Bell P, Goodare H, Hanley B, et al.2014. Patient and public involvement in the early stages of clinical trial development: a systematic cohort investigation. BMJ Open. 2014;4:e005234 highlight decreasing PPI in paediatric research which might fit with the challenges you report.

20. In the discussion section I struggled with the third paragraph about the role of the RCPCH is monitoring time for professional activities. Is this to provide insight into the challenge articulated by RCPCH members about a lack of dedicated time to engage in PPI? I think this needs to be directly related to your results as it seems a little disjointed to me.

RESPONSE: This has been modified.

REVIEWER: 2

The authors address an area of major importance, that is, the voice of the patient and their parents in the decision making, development and organisation of child health services and research.

RESPONSE: We thank the reviewer for their kind comments

The data provided stems from a questionnaire sent to Consultant/SAS Paediatricians who are members of the RCPCH. The response rate is below the 70% cut off to be assured of representative sampling (<50%).

RESPONSE: We appreciate this and discuss it as a limitation, but it represents the opinion of a large number of paediatricians.

The questionnaire has an element of leading questions (i.e. Patients and the public are involved in service improvement in my organisation, but it can be tokenistic).

RESPONSE: We now acknowledge this as a limitation.

*In the results section it would be interesting to read what the respondents themselves are doing or have tried and mention as what works well (if any data is available in that area).

RESPONSE: We have included some case stories

*The discussion reads more like an advertisement for the resources the RCPCH offers in PPI and could be enhanced by a discussion of practice in other areas that have shown success, e.g. via the NIHR CRN. Childhood PPI might also be framed in societal terms, that is how the child/young person's voice is valued in the UK and how this may differ from other countries. This then might lead to different interventions.

RESPONSE: We have now included further discussion.

*Other work such as the Horizon 2020 project on Models of Primary Healthcare for Children focuses on hearing from children directly in matters of autonomy, voice in treatment.

RESPONSE: We have now included this.

There are several YPAG in the country, one of which is YPAG-NE which challenges the notion that running such a group requires much designated SPA time.

RESPONSE: We have added further discussion.

In summary, the sample may not be representative of views and potentially not reflect what is actually happening with regards to PPI. The discussion could do with a wider context.

RESPONSE: We have added further discussion.

VERSION 2 – REVIEW

REVIEWER	Reviewer name Miss Julie Menzies Institution and Country Nurse Researcher, Paediatric Intensive Care Unit, Birmingham Women's and Children's NHS Foundation Trust, Steelhouse Lane, Birmingham. B4 6NH Competing interests Nil
REVIEW RETURNED	22-Feb-2018
GENERAL COMMENTS	Thank you to the authors for considering and addressing my previous comments / observations. Overall the paper reads and flows much better. Points below listed in chronological order, not priority. I hope these are helpful in developing the discussion section further as this paper offers an interesting insight into the challenges researchers face in conducting PPI.

	<p>1. Just a minor point, but in the aims 'what challenges they perceived in conducting PPI'.</p> <p>2. Last line of page 3- Unclear about the statement 'reported the work undertaken by the RCPCH to address these needs'. Aims (as I understand them) 1. survey participants understand whether they feel supported by their organisation to a. undertake PPI in research b. clinical improvement work, 2. Understand challenges to conducting PPI 3. Identify participants perceptions of how RCPCH can support them to engage in PPI. Questions did not specifically ask participants about what work they knew the RCPCH to be undertaking?</p> <p>3. The figure is a useful addition to help with clarifying respondents' views. Visually I wondered if the impact was larger if the scale went to 100% on the Y axis?</p> <p>4. Thank you for the additional detail about how many respondents provided an answer about what worked well in undertaking PPI. As the question did not appear to be a tick box response, I wondered if better wording might be 'indicated they had experience, but then less than 30% provided any detail of this'.</p> <p>5. As approximately 100 people did provide some idea of what works well and why, would it be possible to provide some indication of key themes? It is very clear that PPI is challenging so some positive feedback from members who have experiences success in undertaking would be beneficial, even if this is low numbers.</p> <p>6. The discussion section would still benefit from some restructuring. I feel the aims and results flow well but within the discussion it is hard to see the findings directly related to literature surrounding PPI.</p> <p>7. There is a clear message that participants do not feel organisations value PPI, either for service improvement or research. I would like to see this compared / contrasted with other literature, either about clinicians' / researchers' attitudes or organisational attitudes. Within the research literature there are some references to when PPI might be viewed more favourably by investigators-eg in blinded studies or trials involving a placebo; higher risk studies (Gamble et al 2014).</p> <p>8. There is a useful synopsis on page 8 about the documents available in the public domain and reference to the fact that the majority of paediatricians had not accessed them. Reasons for this would then seem to flow from this, with a review of what other researchers' have found challenging about conducting PPI. Lack of time and representativeness are alluded to in the PPI literature eg Buck et al 2014 (interviews with researchers) so it would be good to strengthen your findings with reference to similar work.</p> <p>9. There is heavy description of work that has been conducted on pages 7,8 & 9. I agree with reviewer 2 that examples of where there has been success in conducting PPI are useful, but reference to all initiatives is currently too detailed. Identifying key initiatives should be sufficient.</p> <p>10. There are numerous suggestions made by participants about how the RCPCH can support PPI activity. Discussing these in relation to the literature would also be useful. What is known about success in PPI? Success has been linked to utilising existing PPI groups eg YPAG groups. If these are in existence why do members not use them? Is the issue that participants' themselves do not value PPI (rather than the organisations)? Or are they not aware of resources / can't access them, or choosing not to utilise them?</p> <p>11. Following on from this it would be useful to see some suggestions of future work / research to be undertaken.</p>
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REVIEWER	Reviewer name Rachel Agbeko Institution and Country Great North Children's Hospital Newcastle upon Tyne UK Competing interests none
REVIEW RETURNED	25-Feb-2018
GENERAL COMMENTS	Many thanks for your considered responses. I have no further questions.

VERSION 2 – AUTHOR RESPONSE

REVIEWER: 1

Thank you to the authors for considering and addressing my previous comments / observations.
Overall the paper reads and flows much better.

RESPONSE: We thank the reviewer for their kind comments.

Points below listed in chronological order, not priority. I hope these are helpful in developing the discussion section further as this paper offers an interesting insight into the challenges researchers face in conducting PPI.

1. Just a minor point, but in the aims 'what challenges they perceived in conducting PPI'.

RESPONSE: This has been altered.

2. Last line of page 3- Unclear about the statement 'reported the work undertaken by the RCPCH to address these needs'. Aims (as I understand them) 1. survey participants understand whether they feel supported by their organisation to a. undertake PPI in research b. clinical improvement work, 2. Understand challenges to conducting PPI 3. Identify participants perceptions of how RCPCH can support them to engage in PPI. Questions did not specifically ask participants about what work they knew the RCPCH to be undertaking?

RESPONSE: We have further clarified that it was our aim to report the work currently undertaken by the RCPCH to address those needs.

3. The figure is a useful addition to help with clarifying respondents' views. Visually I wondered if the impact was larger if the scale went to 100% on the Y axis?

RESPONSE: We altered the figure as suggested, but this resulted in a large amount of white space above each histogram, so suggest it is better remains as we had previously submitted.

4. Thank you for the additional detail about how many respondents provided an answer about what worked well in undertaking PPI. As the question did not appear to be a tick box response, I wondered if better wording might be 'indicated they had experience, but then less than 30% provided any detail of this'.

RESPONSE: This has been modified.

5. As approximately 100 people did provide some idea of what works well and why, would it be possible to provide some indication of key themes? It is very clear that PPI is challenging so some positive feedback from members who have experiences success in undertaking would be beneficial, even if this is low numbers.

RESPONSE: Only approximately 100 respondents made any comments and the responses were varied with small numbers for each, hence we do not feel this information would be valuable.

6. The discussion section would still benefit from some restructuring. I feel the aims and results flow well but within the discussion it is hard to see the findings directly related to literature surrounding PPI. RESPONSE: Having taken out paragraph two, we feel the discussion does well demonstrate findings directly related to the literature surrounding PPI eg. the literature of RCPCH&Us [4], then the various guidelines that have been produced [5, 10, 17], finally, literature about the &Us Engagement Collaborative and how this Collaborative has been involved in PPI activity [11-14].

7. There is a clear message that participants do not feel organisations value PPI, either for service improvement or research. I would like to see this compared / contrasted with other literature, either about clinicians' / researchers' attitudes or organisational attitudes. Within the research literature there are some references to when PPI might be viewed more favourably by investigators-eg in blinded studies or trials involving a placebo; higher risk studies (Gamble et al 2014).

RESPONSE: The Gamble paper looks at trials from 2006-2010 when PPI involvement was not mandatory by certain funders. Indeed, the data included were only from studies which were funded – thus a very select sample so the results are not generalisable. We have now included discussion about this paper. We are unaware of any other surveys of doctors' perception of their organisation's attitudes to PPI.

8. There is a useful synopsis on page 8 about the documents available in the public domain and reference to the fact that the majority of paediatricians had not accessed them. Reasons for this would then seem to flow from this, with a review of what other researchers' have found challenging about conducting PPI. Lack of time and representativeness are alluded to in the PPI literature eg Buck et al 2014 (interviews with researchers) so it would be good to strengthen your findings with reference to similar work.

RESPONSE: We have now included information from the Buck et al 2014 paper and other similar work, but clearly from our paper there have been much work producing guidance etc since that paper.

9. There is heavy description of work that has been conducted on pages 7,8 & 9. I agree with reviewer 2 that examples of where there has been success in conducting PPI are useful, but reference to all initiatives is currently too detailed. Identifying key initiatives should be sufficient.

RESPONSE: As re Editor-in-Chief, paragraph two of the discussion has been removed. The other discussion was added in response to the request for more information.

10. There are numerous suggestions made by participants about how the RCPCH can support PPI activity. Discussing these in relation to the literature would also be useful. What is known about success in PPI? Success has been linked to utilising existing PPI groups eg YPAG groups. If these are in existence why do members not use them? Is the issue that participants' themselves do not value PPI (rather than the organisations)? Or are they not aware of resources / can't access them, or choosing not to utilise them?

RESPONSE: We had already stated in our discussion that despite the support the RCPCH provides for PPI activity we need to be more effective in publicising to our members what we are doing to support PPI activity. Our survey, as shown in the supplementary information now the table, did not ask if the participant valued PPI so we cannot answer the reviewer's question. Equally we cannot respond to the question – are they not aware of the resources/can't access them (unlikely as they are on the RCPCH website which all members can access) or choose to ignore them. We have already included how RCPCH's resources re PPI have been used to benefit [11-15].

11. Following on from this it would be useful to see some suggestions of future work / research to be undertaken.

RESPONSE: In our conclusion we had already included future work namely that the RCPCH has a key role to enable all health professionals to work with children, young people and their parents and carers to improve the quality of research and clinical services. We have added in paragraph one we intend to be more effective in publicising to our members what RCPCH resources are available.

REVIEWER: 2

Many thanks for your considered responses. I have no further questions.

RESPONSE: Thank you.