

PEER REVIEW HISTORY

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

ARTICLE DETAILS

TITLE (PROVISIONAL)	Better Use of Data to improve parent Satisfaction (BUDS): Protocol for a prospective before-and-after pilot study employing mixed methods to improve parent experience of neonatal care.
AUTHORS	Sakonidou, Susanna; Andrzejewska, Izabela; Kotzamanis, Sophia; Carnegie, Wendy; Nakubulwa, Mable; Woodcock, Thomas; Modi, Neena; Bell, Derek; Gale, Chris

VERSION 1 – REVIEW

REVIEWER	Reviewer name: Mandy Daly Institution and Country: Irish Neonatal Health Alliance, Ireland Competing interests: None
REVIEW RETURNED	08-May-2019

GENERAL COMMENTS	<p>Very encouraging to see the collaborative involvement of patients in this study. The topic is indeed a very relevant one. Line 143, there is a reference made to parent/child bonding being adversely affected by stress. Further in the manuscript (line 178) reference is made to bonding and attachment being affected. For consistency and by virtue of the fact that bonding and attachment are different entities it might be advisable to include the word attachment in line 143 also. Allowing 10 mins to interview staff seems short when compared to the time allocated to parent interviews. I think I would not place a time constraint on the interview time(s) in writing in the manuscript in order to optimise the opportunity to capture valuable data.</p> <p>Can I enquire if the decision to exclude parents under the age of 16 is a legal requirement in the UK? This cohort, if English speaking might also provide some useful feedback as to what information is needed by younger parents.</p> <p>Overall this is a very interesting manuscript and the study has potential to develop much needed tools . Well done.</p>
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REVIEWER	Reviewer name: Lars Ursin Institution and Country: NTNU, Norway Competing interests: None
REVIEW RETURNED	10-May-2019

GENERAL COMMENTS	The paper is a description of a hypothetical study, not an actual one. When the study is conducted, a paper on the findings will be interesting to read.
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REVIEWER	Reviewer name: Inger Hilde Hagen Institution and Country: Norwegian University of Science and Technology Competing interests: none
REVIEW RETURNED	24-May-2019

GENERAL COMMENTS	This seems to be a protocol for a pilot-study, and it should appear in the headline.
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	<p>page 6 line 148: what is NHS?England survey...</p> <p>page 7 line 184: what is BUDS?, the hospital Chelsea and Westminster are not described in relation to level of the NICUs, how many children are treated per year etc.</p> <p>page 10: the PEC-survey is claimed to be a validated instrument; you have to report cronbachs' alpha, and describe the Likert scale. perhaps this will be reported when publishing the results of the study?</p> <p>is there a Likert scale in the question given to the staff members?</p> <p>have you prepared an interview guide?</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Comment 1:

“Line 143, there is a reference made to parent/child bonding being adversely affected by stress. Further in the manuscript (line 178) reference is made to bonding and attachment being affected. For consistency and by virtue of the fact that bonding and attachment are different entities it might be advisable to include the word attachment in line 143 also.”

Response:

Thank you for pointing out this inconsistency. As advised, we have included the word ‘attachment’ in page 6, line 142.

Comment 2:

“Allowing 10 mins to interview staff seems short when compared to the time allocated to parent interviews. I think I would not place a time constraint on the interview time(s) in writing in the manuscript in order to optimise the opportunity to capture valuable data.”

Response:

We appreciate 10 minutes may seem short when compared to the time allocated to parent interviews. However, our preliminary work has indicated that staff members are able to address questions around communication in a very focused way and 10 minutes have been sufficient, whereas parents tend to need more time to allow for a more emotional response. Additionally, as staff will be interviewed during their lunch break, we feel 10 minutes would be an appropriate length of time to ask of them. Consequently, the ethics committee has already approved this amount of time for staff interviews in our methodology plan. If we find that during interviews we are not able to capture enough data we can consider applying to the ethics committee for a substantial amendment for longer interview times.

Comment 3:

“Can I enquire if the decision to exclude parents under the age of 16 is a legal requirement in the UK? This cohort, if English speaking, might also provide some useful feedback as to what information is needed by younger parents.”

Response:

Excluding parents under the age of 16 is not a legal requirement in the UK. We have opted to exclude them as they represent a particularly vulnerable population, in addition to the already vulnerable parents in neonatal care. Working with parents under the age of 16 would require more resource to provide specialist emotional support for them, which would be difficult in the context of our pilot study.

Following our study completion we hope to be able to include parents of all ages in a larger subsequent study as gaining feedback from all cohorts would be very useful.

Reviewer: 2

Comment 1:

"The paper is a description of a hypothetical study, not an actual one. When the study is conducted, a paper on the findings will be interesting to read."

Response:

Thank you for your comment; we indeed plan on publishing our findings once our study is completed. Our manuscript has been submitted under the 'Protocols' category, in an effort to be transparent and publish our methodology ahead of publishing our results. We have amended our title to make it more obvious that this paper is a study protocol. The new title is "Better Use of Data to improve parent Satisfaction (BUDS): Protocol for a prospective before-and-after pilot study employing mixed methods to improve parent experience of neonatal care."

Reviewer: 3

Comment 1:

"This seems to be a protocol for a pilot-study, and it should appear in the headline."

Response:

Thank you for pointing this out; please see our response to Reviewer 2's comment.

Comment 2:

"page 6 line 147: what is NHS?England survey..."

Response:

NHS England is the executive body of the department of Health, overseeing the budget, planning and delivery of the National Health Service (NHS) in England. For more clarity, we have amended this on page 6, line 147 to read: The latest national UK survey of parents' neonatal experiences found that..."

Comment 3:

"page 7 line 184: what is BUDS?"

Response:

On page 7, line 184: "A BUDS study steering group was formed", BUDS refers to our study's title BUDS (Better Use of Data to improve parent Satisfaction). For more clarity, we have amended this on page 8, line 183 to read: "A study steering group for the Better Use of Data to improve parent Satisfaction (BUDS) project was formed".

Comment 4:

"the hospital Chelsea and Westminster are not described in relation to level of the NICUs, how many children are treated per year etc."

Response:

Thank you for pointing this out. We have added the following description on page 9, line 230: "This neonatal unit in London, United Kingdom, provides tertiary level neonatal intensive care, including specialist surgical care, with 750 annual admissions and a 36-cot capacity."

Comment 5:

"page 10: the PEC-survey is claimed to be a validated instrument; you have to report cronbachs`alpha, and describe the Likert scale. perhaps this will be reported when publishing the results of the study?"

Response:

In terms of validation, we have completed our survey's qualitative cognitive testing and are currently using preliminary survey data to conduct a survey validation study. As per your comment, we plan on reporting this when publishing our study findings.

For more clarity we had added the following on page 10, line 253: "The PEC survey is an adaptation of the original UK national Neonatal survey 2014 carried out by the Picker Institute. We have completed qualitative cognitive survey testing with parents on the Chelsea and Westminster neonatal unit and are currently conducting a survey validation study, using preliminary survey data. The PEC study will be published once validation analysis is completed".

Comment 6:

"is there a Likert scale in the question given to the staff members?"

Response:

The staff survey consists of 3 questions as described on page 11, lines 281-284. These are not Likert scale questions. The first one is a yes/no question and for the remaining two questions staff are asked to respond by inserting a "number of times". We did not include a Likert scale in order to avoid staff members over or underestimating the frequency of conversations they were having with parents.

Comment 7:

"have you prepared an interview guide?"

Response:

Yes. We are attaching our parent and staff interview guides as supplementary files. We have referenced these on page 11 line 276 "(see online supplementary additional file 1)" and 278 "(see online supplementary additional file 2)".