Author’s response to reviews

Title: How to measure the need for transition to adult services among young people with Attention Deficit Hyperactivity Disorder (ADHD): a comparison of surveillance versus case note review methods

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Author’s response to reviews:

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Dear Editors,

Thank you for considering our paper (BMRM-D-18-00407) entitled “How to measure the need for transition to adult services among young people with Attention Deficit Hyperactivity Disorder (ADHD): a comparison of surveillance versus case note review methods” (authors Eke
H, Janssens A, Downs J, Lynn RM, Ani C, and Ford T.) for publication in BMC Medical Research Methodology. We appreciate the opportunity to revise the manuscript and resubmit following the reviewers comments.

We would like to thank the reviewers for their helpful comments, which we have read through and addressed in the revised manuscript. Our responses to the reviewers’ individual comments are described below:

Reviewer 1:

Comment 1: While technically accurate, reporting in the abstract that case record review yielded four times as many cases as surveillance is misleading. Most readers would assume case record review must be four times as efficient, but this is incorrect as the denominator is unknown. Given case record review had a limited catchment while the surveillance was nationwide, case record review was in all probability far more efficient than surveillance.

We acknowledge that this could be misleading. The abstract has been revised to state the cases reported, and the methodological issues of both methods (see p2, lines 15-20).

Comment 2: Like the respondents, I too found surveillance case definition criterion 1 ambiguous. It is a shame the problem was not detected in the pilot phase of the project.

We acknowledge that the reviewer, like some of the clinicians reporting cases, found the definition difficult or ambiguous as reported in the paper. The definition was developed through many iterations with staff at BPSU and CAPSS, and individual clinicians before the study went live. The first month of surveillance was discarded in order to account for any misunderstandings in the criteria or errors in reporting (see p6, line 9 for further information). Queries regarding the case definition were resolved directly with the clinician, but most queries only occurred at the beginning of the surveillance period, and hence would have been considered in the ‘pilot’ month. We have included additional explanation to this end (see p11, line 7).

Comment 3: on p10 it states there were 300 CAPSS case notifications. This figure does not reconcile with the data reported in Table 3.

The figure of 300 CAPSS case notifications was the total number of cases received from the whole surveillance study, which covered the whole of the UK, for twelve months. The data reported in Table 3 only refers to the cases notified within London, and therefore as a comparison to the case note review via CRIS. We have added a sentence to clarify this in the results section (see p10, line 22).
Comment 4: the word ‘data’ is consistently treated as singular. It is plural.

Thank you for highlighting this error. It has been amended throughout the manuscript.

Comment 5: Bottom p13 last sentence there is a redundant ‘other’.

This has been deleted.

Comment 6: My interpretation of the data is that neither approach was very successful. I do not think the recommendation that the two should be used in combination is justified. The next step would be to refine the methodology to improve yield, or to develop a different method altogether. If a stimulant register exists in the UK as it does in other jurisdictions, this could be a way in. Those registered as continuing to receive stimulant medication and falling within the age band typically associated with transition could be contacted.

We feel that we have addressed the methodological issues for both methods at length within the discussion. Whilst the use of stimulant registers in the UK would allow us to identify a caseload of young people on medication for ADHD who may be in the age bracket for transition, we are limited by data protection governance that does not permit linkage in order to ascertain positive cases. We acknowledge however that further work would be needed with both methodologies to improve the robustness of the data that are collected. We have added to the discussion and conclusion to acknowledge this (see p16 line 19, and p17 line 24).

Reviewer 2:

We thank you for your comments regarding our manuscript, and the recommendation for acceptance without revision.

This manuscript concludes that this is the first study to survey the incidence of transition and the first study to directly compare two existing methods of quantifying transition. The strengths and weaknesses of both methodologies are discussed at length. The comparison was limited by the inability to directly link cases for ascertainment, however we believe the findings provide a valuable insight into transition in ADHD that has not been achieved by previous studies

To confirm, this work is original, has not been published previously, and is not under consideration for publication elsewhere currently. There are no conflicts of interest to disclose. For any further correspondence concerning this review, please contact h.e.eke@exeter.ac.uk.
Thank you for the opportunity to resubmit the manuscript with revisions, and I hope you will find it of interest. I look forward to hearing from you.

Kind regards,

Miss Helen Eke