

## 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 families in the UK use to manage Attention Deficit Hyperactivity Disorder (ADHD): a survey of resource use.
<b>AUTHORS</b>	Fibert, Philippa Relton, Clare

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Reviewer name: Dr. Melissa L. Danielson Institution and Country: Ctr Dis Control, 4770 Buford Highway NE MS S106-4, Atlanta, Georgia, United States Competing interests: None
<b>REVIEW RETURNED</b>	29-Jul-2020

<b>GENERAL COMMENTS</b>	<p>This manuscript provides interesting information about the frequency with which non-traditional treatments are being used for children with ADHD in a convenience sample in the UK, which is important given the limited evidence regarding the effectiveness of these treatments. While the research question is significant, I have a number of concerns that could be addressed to strengthen this manuscript.</p> <p>Introduction</p> <ul style="list-style-type: none"> <li>- Page 5, lines 13-17 – it would be good to add a reference (or several) for list of co-occurring problems</li> <li>- Page 5, lines 39-60 – the flow of the text is a little difficult with the paragraph formatting choices; a revision to improve readability would be helpful.</li> <li>- Table 1 – it would be helpful to have more information about these studies to evaluate the reported frequencies of non-mainstream treatment across samples. In particular, the age of the population and method of sample recruitment (i.e. clinical or convenience sample? Or population-based sampling?) would be important characteristics to provide information on.</li> <li>- It might help the flow of the manuscript to add a paragraph to the end of the introduction to present the reason for this study and how it relates to other work in the published literature.</li> </ul> <p>Methods</p> <ul style="list-style-type: none"> <li>- The information about the patient public involvement might be better suited to be included in the introduction or in supplemental materials, as this material appears to be more background information for the study as opposed to the methods for this specific study.</li> <li>- The study is referred to a pilot in the abstract and reference to a larger data collection is mentioned in the discussion, but there doesn't seem to be information in the methods section describing how this pilot fits within the overall study design.</li> <li>- Were the questions about types of treatments received intended to capture all treatments ever received by the child? Or was it specific to a set time period? Did the question specify whether the treatments were received for ADHD, or were parents reporting on treatments that may have been given for other conditions or</li> </ul>
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	<p>problems? Could this have affected what the parents reported on for the open-ended question?</p> <p>Results</p> <ul style="list-style-type: none"> <li>- Table 2 - Since a major limitation of the study is that many of the reported treatments used were provided as responses to the open-ended question, it might be helpful to provide an indicator in the table to note which treatments was specifically asked about on the questionnaire, and which were categorized from the open-ended responses.</li> </ul> <p>Discussion</p> <ul style="list-style-type: none"> <li>- It would be helpful to have more information provided in Figure 1 and Figure 2, as it is not immediately obvious what the bars represent or what the numbers correspond to (a footnote indicating that details on the other surveys are provided in Table 1 might help)</li> <li>- Page 13, line 54-55 – the comment that recruitment of a larger sample providing more representative information is not entirely accurate; deliberate sampling approaches and alternative study designs could also be used to produce estimates that are representative of a given population.</li> <li>- Page 15, lines 3-23 – the paragraphs about nutritional interventions and homeopathy could benefit from a sentence or two tying that information back to the results presented in this study (e.g. talking about the portion of the population of children with ADHD who are already using these treatments or how they may or may not benefit from use of these treatments).</li> </ul> <p>Conclusion</p> <ul style="list-style-type: none"> <li>- Page 15, line 28 – the study population is described as a “representative sample of the ADHD population”, but the methods indicate that this is a convenience sample of families willing to participate in a research cohort; this is unlikely to be representative of the whole population of families of children with ADHD.</li> </ul>
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### VERSION 1 – AUTHOR RESPONSE

Reviewer comment. Reviewer 1	Response
Page 5, lines 13-17 – it would be good to add a reference (or several) for list of co-occurring problems	References have been added for each of the co-occurring problems listed in the introduction. We have also added percentages of co-occurrence where stated by the authors.
- Page 5, lines 39-60 – the flow of the text is a little difficult with the paragraph formatting choices; a revision to improve readability would be helpful	We have tried to improve readability. This text now reads: <i>“For the purposes of this article such treatments will be referred to as ‘non-mainstream’. Other descriptive terms for non-mainstream are ‘complementary and/or alternative medicine’ referring to a broad set of healthcare practices that are not part of that country’s own tradition or conventional medicine and not fully integrated into the dominant healthcare system,[13]. Another term used is ‘integrative’, where conventional and complementary approaches are used in a co-ordinated way (<a href="https://nccih.nih.gov">https://nccih.nih.gov</a>). Treatments move from non-mainstream to mainstream as their evidence base and/or acceptability grows.</i>

	<p><i>Non-mainstream treatments are also described as 'natural',[14]. Although doctors can be uncomfortable recommending treatments about which they are unknowledgeable and untrained,[15] there is a growing interest in using natural medicines, particularly in Paediatrics, [16, 17]."</i></p>
<p>Table 1 – it would be helpful to have more information about these studies to evaluate the reported frequencies of non-mainstream treatment across samples. In particular, the age of the population and method of sample recruitment (i.e. clinical or convenience sample? Or population-based sampling?) would be important characteristics to provide information on.</p>	<p>Two extra columns have been added to Table 1: age; and sample type (clinical, population, convenience), together with a more detailed description of the sample. More detail has been added to the 'Setting' column: instead of just stating the country, we have added the state/county/district/hospital.</p>
<p>It might help the flow of the manuscript to add a paragraph to the end of the introduction to present the reason for this study and how it relates to other work in the published literature.</p>	<p>Thank you. The following sentences have been added at the end of the introduction: <i>"No surveys were identified in the UK. This survey seeks to address this gap. Data about resource use was collected from a convenience sample of families recruited to the STAR (Sheffield Treatments for ADHD Research) project. The project used Trials within Cohorts (TwICs) methodology [17], whereby first a large observational cohort of participants with the condition of interest was recruited and their outcomes of interest regularly measured."</i></p> <p><i>This report describes the resource use reported by cohort participants at entry into the observational cohort (Appendix 1)[48]. Results of the pilot randomised controlled trials conducted within the cohort, and detailed population characteristics, are reported elsewhere"</i></p>

<p>Methods</p> <p>- The information about the patient public involvement might be better suited to be included in the introduction or in supplemental materials, as this material appears to be more background information for the study as opposed to the methods for this specific study.</p>	<p>Much of the PPI section has been moved to the Introduction.</p> <p>As a result of PPI involvement an additional question was added: <i>"Please use this space if there's anything else you'd like to tell us about your child"</i>. this question was added to the list of questions in the Recruitment section of Methods. We realised that responses to this question had not been included in our first draft, so we have added these responses to the end of the Results section.</p> <p>The last paragraph of the original PPI section, and two other sentences, have now been incorporated in the Discussion, as recommended by the Editor in Chief.</p>
<p>- The study is referred to a pilot in the abstract and reference to a larger data collection is mentioned in the discussion, but there doesn't seem to be information in the methods section describing how this pilot fits within the overall study design.</p>	<p>The term 'pilot' is not relevant to the survey and refers to the subsequent trials, so we have removed the term 'pilot' when referring to the survey.</p>
<p>- Were the questions about types of treatments received intended to capture all treatments ever received by the child? Or was it specific to a set time period? Did the question specify whether the treatments were received for ADHD, or were parents reporting on treatments that may have been given for other conditions or problems? Could this have affected what the parents reported on for the open-ended question?</p>	<p>We have added to this sentence in the Recruitment section of Methods: <i>"Carers were asked questions intended to capture all treatments ever received by the child, not specifically for their ADHD"</i>.</p> <p>We have also ensured that the time frame requested for every question is specified. The questionnaire is now included at the end of this manuscript as Appendix 1, where the time frame for each question can be seen.</p> <p>As treatments did not need to be specific to ADHD, we have refined the survey Objective of our survey to <i>"manage their 'children with ADHD'"</i> rather than <i>"children's ADHD"</i></p> <p>We have added this sentence to the discussion section: <i>"There are advantages and disadvantages of each question type: the use of an open-ended question allowed the broad spectrum of treatments being used to be represented...."</i>.</p>
<p>Results</p> <p>- Table 2 - Since a major limitation of the study is that many of the reported treatments used were provided as responses to the open-ended question, it might be helpful to provide an indicator in the table to note which treatments was specifically asked about on the questionnaire, and which were categorized from the open-ended responses.</p>	<p>Thank you for this suggestion. An extra column has been added to the relevant Tables describing whether the question type is open-ended or specific.</p>
<p>Discussion</p> <p>- It would be helpful to have more information</p>	<p>For clarity we decided to replace the figures with description within the text: <i>"Sample sizes of</i></p>

provided in Figure 1 and Figure 2, as it is not immediately obvious what the bars represent or what the numbers correspond to (a footnote indicating that details on the other surveys are provided in Table 1 might help)	<i>surveys conducted in other countries range from 73-822. Ours was 175. At 31%, our non-mainstream treatment use is slightly less than median usage found in other surveys (range 12-71%) (Table 1)."</i>
- Page 13, line 54-55 – the comment that recruitment of a larger sample providing more representative information is not entirely accurate; deliberate sampling approaches and alternative study designs could also be used to produce estimates that are representative of a given population.	Thank you for this. We have deleted this sentence.
- Page 15, lines 3-23 – the paragraphs about nutritional interventions and homeopathy could benefit from a sentence or two tying that information back to the results presented in this study (e.g. talking about the portion of the population of children with ADHD who are already using these treatments or how they may or may not benefit from use of these treatments).	Thank you. We have added text tying the research evidence to the survey evidence: <i>"Evidence for the two most popular treatments according to our survey (nutrition and homeopathy) is mixed, but more pragmatic, outcome oriented trial evidence suggests their effectiveness. This is arguably the more useful trial design for patients considering these non-specific, complex treatments."</i>
Conclusion - Page 15, line 28 – the study population is described as a "representative sample of the ADHD population", but the methods indicate that this is a convenience sample of families willing to participate in a research cohort; this is unlikely to be representative of the whole population of families of children with ADHD.	We have removed all mention of 'representativeness' from the conclusion. In the discussion we have amended the first sentence to: <i>"this convenience sample is broadly representative of the ADHD population in terms of co-diagnoses, which are estimated to occur in 40-65%"</i>
Associate Editor Comments to the Author:	
I would agree with the reviewers comments- this is a very useful study and provides valuable information about a common paediatric condition. But there are deficiencies in the reporting of the methods and analysis as pointed out in the review. Additionally the Abstract must provide more information about the type of study and the sampling- ie that this is a convenience sample of families willing to participate in a research cohort.	<p>Thank you for your positive comments. The abstract now describes the sample as "A convenience sample of participants in the UK who consented to join an observational cohort".</p> <p>The Design section of Methods now states that <i>"this survey reports the responses from UK families with children who <b>agreed to</b> participate in an observational cohort"</i>.</p> <p>The final paragraph of the discussion now states <i>"This is a convenience sample of participants in the UK who consented to recruit to a cohort, and it may be that dissatisfaction with conventional care drew them towards participation. Never the less results from our survey do not deviate substantially from the results from population and clinical samples."</i></p>
Editor in Chief	
Add the questionnaire as a supplementary file. Page 9 line 33 implies that it is there, but within the PDF it does not exist.	The questionnaire has been added at the end of the manuscript
Confirm ethical approval for the survey was given and add text stating this.	We have added the following text: <i>"The STAR project (including the survey) was sponsored by the University of Sheffield (URMS number 143647), and approved under the University of</i>

	<i>Sheffield's Ethics Review Procedure by the School of Health and Related Research (SchARR) Research Ethics committee (REC) on 30/4/15, application number 003424,[25].</i>
Abstract Results. Do NOT mention the denominator (175) after every result.	The denominator has been removed from all but the first mention
Abstract Conclusions. Delete the 2nd & 3rd sentences as they are not conclusions. Results p10,line 15. Replace "average" with "mean"	The 2nd & 3rd sentences have been deleted. 'Average' has been replaced by 'mean'
Patient public involvement section. The last paragraph would be better in the Discussion.	As recommended by reviewer 1, most of the PPI section has been moved to the Introduction. We realised that PPI information about the subsequent RCT steering committee was not relevant to the survey, so we have removed this. The question included on PPI recommendation "Please use this space for anything else you would like to tell us) has been put in the Methods section. And the responses to this question have been added to the Results section
Additional diagnoses would be better in a Table. You can then reduce the text.	A new table (Table 2) has been added for additional diagnoses.
Results Do NOT repeat the information in the table as text. Summarise instead. Do NOT mention the denominator (175) after every result.	The denominator has been removed from all but the first mention. Repetition of tabular results has been minimised/synthesised, and percentages and fractions referred to instead
Table 2 needs dividing into three tables- one for medicines; one for non-mainstream therapies and one for the remainder. When listing individual medicines/activities etc do so numerically, ie highest number first, lowest number last	Table 2 is now Tables 3-5, and listings ordered as advised
Table 1 and the accompanying text would be better in the Discussion.	Table 1 has been removed from the introduction and is now provided as a separate document (in landscape format). Much of the description of other surveys has been moved to the discussion section, where three paragraphs compare our survey with the 10 other surveys.
Discussion try and avoid repeating results. Better to state "almost three quarters of parents attended a parenting class"	Thank you, we now refer to percentages and fractions and in a more discursive way, rather than repeating the results.
When discussing homeopathy, refer to the Cochrane review of 2005 and its findings re lack of evidence supporting its use for ADHD.	The 2007 Cochrane review is now referred to and discussed: <i>"Three RCTs testing the efficacy of individually tailored homeopathic medicines,[36-38] and one testing the efficacy of a generic homeopathic product,[39] were synthesised in a Cochrane review [40] which overall found little evidence of efficacy and recommended development of optimal treatment protocols. Subsequently 2 further RCTs testing the effectiveness of treatment by homeopaths,[18, 41] and one testing the efficacy of a generic homeopathic product,[42] have been conducted."</i>
Your paper needs a MAJOR rewrite. I strongly advise you to look at previous papers describing results of surveys.	We have looked at other studies for guidance and endeavoured to act on the detailed comments provided by reviewers. Thank you for this opportunity to learn and improve our article.

