## PEER REVIEW HISTORY

## ARTICLE DETAILS

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| **TITLE (PROVISIONAL)** | Protocol for the mixed methods Managing young people (aged 16-25) with Attention deficit hyperactivity disorder in Primary care (MAP) study: mapping current practice and co-producing guidance to improve healthcare in an underserved population. |
| **AUTHORS** | Price, Anna; Smith, Jane; Mughal, Faraz; Salimi, Anita; Melendez-Torres, G.J; Newlove-Delgado, Tamsin |

## VERSION 1 – REVIEW

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| **REVIEWER** | Shrestha, Mahesh. |
| **REVIEW RETURNED** | 09-Nov-2022 |

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| **GENERAL COMMENTS** | Good paper and well planned.<br>Few minor corrections:<br>1. Consider sentence correction in Page 9 Line 59 under WP2 Data collection- 'affects study take up' could be reworded to 'take up of study'.<br>2. Page 14 Line7 under Funding-sentence ending in 'and.' Page 14 Line 9, sentence with sponsor and Protocol, consider changing from capital' S' and "P' for Sponsor and Protocol to ' sponsor' and 'protocol'. |

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| **REVIEWER** | Haskell, Brittany<br>Vanderbilt University, School of Nursing |
| **REVIEW RETURNED** | 22-Nov-2022 |

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| **GENERAL COMMENTS** | Title: This title seems very long. Consider making this more succinct. Your title describes the intended population as “young people”, which could be made clearer. Some might interpret this to mean populations younger than 40 for example. You seem to be focusing on the transition between pediatric and adult care, so make this language more focused.<br><br>Abstract:<br>In the introduction, you may want to consider focusing more on language around highlighting gaps in services for this population. While you discuss this in the introduction section, it is not clear in your study aim. I would also like to hear more about what you are hoping to highlight from the research. For example, you are looking for gaps in access to care and population experience of care, etc.<br><br>For all study methods, you outlined some basic timelines, but I think you could have been more concrete on your implementation timeline. When do you plan on your study actually taking place? You could also be more specific on identification of participants. |

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| | You did an excellent job of highlighting the aim of each study method, but these do not seem synthesized accurately when you are talking about the study as a whole.<br>You talk in a few points about improving access to care for this population, but you do not seem to be doing that with this study. Rather, you seem to be highlighting gaps (or strengths) in care (which is very important to identify). It seems that a future study or services might actually be focusing on improving access to care.<br>Some references are older, so you might consider making sure these are foundational articles or updating. |

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| **REVIEWER** | Phillips, Heidi<br>Swansea University, Medicine |
| **REVIEW RETURNED** | 13-Feb-2023 |

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| **GENERAL COMMENTS** | Title: TITLE: Managing young people with Attention deficit hyperactivity disorder in Primary care (MAP), mapping current practice and co-producing guidance to improve healthcare in an underserved population: protocol for a mixed-methods study<br>SHORT STUDY TITLE: Managing young people with ADHD in primary care (MAP) study<br>The management of young people with ADHD in primary care is variable, with NICE guidelines advising that people with ADHD would benefit from improved organisation of care services. The aim of this study is to develop a national map and overview of current primary care provision and prescribing practice, including care pathways, in the management of young people (age 16-25) with ADHD. The study comprises 3 different workstreams, using multi-informant, mixed methodology. The authors are to be commended for including multiple informants to identify regional variations and for the involvement of young people throughout the research.<br>Thank you for the opportunity to comment on the study protocol, although I note that the study is already underway<br>Introduction/Background<br>I think it is important to stress that this study covers England only and care should be taken when referencing national. References relating to prevalence should also make clear whether the authors are referring to national or international prevalence - as it stands it appears as though the authors may be citing research taken from different studies using different estimates. (The author references the Faraone paper, which estimates the prevalence of ADHD in childhood to be 8%, with the prevalence at age 25 to be 1.2%. Faraone et al suggest that 3.2% of adults may have some residual symptoms that do not reach threshold for a full diagnosis. It appears that the author is using 3.2% of 8% to estimate that 40% of young people will continue to experience symptoms into adulthood). It may be more authentic to include up to date, UK-specific estimates of prevalence and impact and if necessary, compare these with international estimates. |

Overall, the background stresses the financial and social implications of a diagnosis of ADHD but in my opinion, the potential role for primary care in the management of a patient with ADHD could be made clearer. ADHD as a lifelong, chronic health condition that impacts all aspects of health could be emphasised as well as the role ADHD plays in the development of other health conditions. This may then help explain the rationale for a greater role for Primary care in the management of ADHD.

Rationale

In terms of the rationale for the study, the authors reference NICE guidance which they suggest highlights the role of primary care services in the provision of care in relation to young people with ADHD. The objectives make clear that their aim is to "improve", "better coordinate" and "improve accessibility" for young people with ADHD, although whether this is to improve all services provided by primary care for young people with a diagnosis of ADHD, to improve the recognition and management of ADHD in young people presenting to primary care, or to provide better ADHD-related information to primary care practitioners could be clarified. I think care must be taken not to imply a responsibility that primary care does not currently have which risks fuelling demand for services that are not available. Primary care practitioners are under no obligation to provide prescribing and monitoring of ADHD medication under shared care arrangements. The responsibility for diagnosis, treatment and management of ADHD currently lies with specialist services, including appropriate transition between child and adult mental health services.

The objectives are also to map prescribing practice and understand practitioners' needs for prescribing support. I have some concerns that the stated objectives imply that the outcomes from the first two work streams have already been pre-decided. Since the rationale for the study is a lack of data relating to primary care provision, then perhaps a re-framing of the rationale and/or study objectives might be helpful?

Strengths and limitations: The strengths and limitations of the study might be better described by considering the strengths and limitations of each of the work packages. As it stands it appears as though there is only one limitation relating to the 3 separate studies that form the overall protocol.

Methods and analysis/Overview

There appear to be 3 stakeholder groups: 1) those involved in the mapping study across England. 2) 30 or so stakeholders involved in semi-structured interviews 3) "stakeholders" who will develop guidance. The membership of each group and whether there is overlap could be clarified.

Work package 1 Survey:

Design.

The study aims to map service provision for children and young people age 16 -25 by sampling information from three key stakeholder groups, with a minimum of 6 responses per ICS. Since the population covered by ICSs range from 500,000 to over 3 million, sampling bias as a result of under-coverage is possible, as is self-selection bias. Adequate representation from each of the stakeholder groups, relative to ICS geographical and population size is essential if the data is to be meaningful, especially if the term “mapping current practice” is to be used. I am not clear as to why anyone with lived experience of ADHD is included in this workstream, which is designed to understand the experiences of those aged 16-25?

The timing of each of the study streams is not explicit. “Recruitment commenced in September 2022” (P3,22) and “The online survey will be open for up to 16 weeks”. (P8, 19), which suggests therefore recruitment is complete.

Data collection:

The survey will include core research questions, detailed in Figure 2. “The survey will be designed (and programmed) so that respondents will be taken to different questions, depending on the stakeholder group that they primarily identify with. Final survey wording will be piloted and agreed in consultation with study RAGs”. Have the final survey questions been determined and have the Ethics Committee had sight of the questions and approved them?

The phrasing of the current questions seems to be aimed more at healthcare providers and commissioners rather than patients and it is doubtful whether a young person with ADHD would or should be able to answer these questions. The questions are in relation to adult ADHD and medications; is it implied that medication for 16 - 18 year olds comes under the remit of adult services?

I would take care with the phrasing of the question, “Do primary care providers provide transitional support for young people with ADHD?” (if this part of the study is still underway). There is currently no requirement or obligation for primary care to provide transitional support and NICE guideline 43 recommends that Health and social care service managers in children's and adults' services are responsible for transition coordination.

Work package 2 Qualitative

Design. It appears that the findings of WP1 are going to be used to identify which geographical areas are going to be chosen for WP2 and within these areas, particular services are going to be examined in more detail to establish “what works” and “what is needed” in terms of service provision as per the abstract.

Two of the three stakeholder groups appear to have been combined for this part of the study. It is not clear as to the rationale for this – do healthcare professionals in primary care have similar perspectives to healthcare commissioners? The rationale for deciding to focus on 3-6 locations and the rationale for the sample sizes could be clarified. I would also appreciate more clarity as to whether the study will comprise of semi-structured interviews with individuals from each group, with each separate group as a whole, or as combined groups with representatives from each stakeholder group and also with respect to the composition of the focus groups.

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| | Data collection<br>It is intended that the interviews/focus groups will “follow topic guides developed and refined in consultation with the research advisory groups” and that “topic guides will be iteratively adjusted”. The schedule for data collection, analysis and meeting of the RAG groups are not included and it is unclear as to how this will work in practice if the RAGs are only meeting every 6 months. The suggested content for the topic guides is appropriate considering the study’s stated objectives, although final topic guides are not included. If the final content of the topic guides is to be determined by the RAG groups based on the findings from workstream 1, it would be helpful if this was stated.<br>It would also be helpful to understand who will be conducting the interviews and/or focus groups, how the interviews will be recorded, the nature of the relationship between the interviewer(s), participants and researcher(s) plus any potential conflict of interest (eg in relation to personal experience of ADHD).<br>Data analysis<br>The analysis methodology is appropriate considering the nature of the study. It would be helpful to know whether multiple coders or other methods of research triangulation will be used. It might be useful for the study authors to obtain feedback from the participants after the analysis to ensure their own meanings are captured appropriately.<br>Work package three (WP3) Co-production<br>Design<br>This workstream is intended to “co-develop guidance using available evidence to improve primary care for young people with ADHD”. The objectives of this workstream are also stated in the study rationale: “to better co-ordinate primary care and improve accessibility for young people with ADHD”. I think care should be taken not to assume the findings of the previous two workstreams are already established. It may also be useful to reference the guidance that is already widely available (eg NICE guidance and National Shared Care protocols in relation to ADHD medication monitoring).<br>Participants<br>It is not clear whether the participants will be recruited from the initial population or following a further recruitment drive for this part of the study. This could be made explicit as there are advantages and disadvantages to both. The number, roles and location of participants would be useful to include to ensure that the findings are as widely applicable as possible. Consideration should be given to including representatives from specialist secondary care services (healthcare commissioners and professionals) amongst the stakeholder group as the management of ADHD in young people is not solely the remit of primary care. Evidence used to co-produce the guidance should also include existing published guidelines so as not to appear as currently it seems as though the guidance relies solely on the perspective of a convenience sample of contributors. |

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| | Conclusion.<br>The anticipated outcomes of this research are likely to reinforce what is already known on this topic ie that provision of services for ADHD is poor and variable across England, that young people's experience of their care is also poor, especially with respect to transitioning from child to adult services, and that primary care healthcare practitioners feel unsupported in regards to specialist advice and support. The current study appears to risk focussing on what should be available from primary care from the patients' perspective, and an attempt to understand what information healthcare professionals need in order to provide it. , in the form of more guidelines. Guidelines relating to diagnosis, management and support for patients with ADHD are widely available and it is questionable whether further guidance aimed at improving primary care will be useful. The semi-structured interview questions aimed at healthcare commissioners will be key to understanding the resistance towards putting guidelines into action and it would be useful if these are included in the study protocol. |

## VERSION 1 – AUTHOR RESPONSE

| Reviewer: 1<br>Mahesh. Shrestha | | |
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| Comments to the Author: | | |
| Good paper and well planned. | Thank you. | |
| Few minor corrections:<br>1. Consider sentence correction in Page 9 Line 59 under WP2 Data collection- 'affects study take up' could be reworded to 'take up of study'. | Thank you, we have changed the wording in line with your suggestion. We agree that this reads more clearly, without changing the meaning of the sentence. | WP2 Data Collection. Sentence wording adjusted for clarity:<br>*This flexible approach draws on evidence that respondents' experience of control and choice affects study take up* <u>*of studies*</u> *[28].* |
| 2. Page 14 Line7 under Funding-sentence ending in 'and.' Page 14 Line 9, sentence with sponsor and Protocol, consider changing from capital' S' and "P' for Sponsor and Protocol to ' sponsor' and 'protocol'. | Thank you for spotting this typo. The additional 'and' has now been deleted. We have also added a funding acknowledgement sentences in line with NIHR requirements for the 3 Schools programme. | Under FUNDING:<br>The '*and'* has been deleted. A sentence has been added to cover the NIHR Three Schools funding acknowledgement.<br><br>The capital 'S' and 'P' for Sponsor and Protocol |

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|  | Thank you for this. This has been addressed. | have been replaced with lower case letters. For consistency, this has also been changed in one other place for 'sponsor' (under Amendments) |
| Reviewer: 2<br>Dr. Brittany Haskell, Vanderbilt University |  |  |
| Comments to the Author: |  |  |
| Title: This title seems very long. Consider making this more succinct. Your title describes the intended population as "young people", which could be made clearer. Some might interpret this to mean populations younger than 40 for example. You seem to be focusing on the transition between pediatric and adult care, so make this language more focused. | Thank you for this comment. As this is the title under which the ethical approval has been issued, we have not been able to reduce the number of words. We have however changed the order so that *Protocol* is at the beginning of the title. We believe this change, alongside the addition of a colon makes it easier to read the title with clarity.<br>In relation to the specificity of 'young people', again this is a helpful observation. We have tried to balance brevity with specificity here. Rather than adding in 16-25 to the title in brackets, we have specified the age-range we mean when referring to 'young people' in the last sentence of the Abstract introduction. | Title changed and with the aim of making it easier to read:<br>"*Protocol for the mixed methods Managing young people with Attention deficit hyperactivity disorder in Primary care (MAP) study: mapping current practice and co-producing guidance to improve healthcare in an underserved population.: protocol for a mixed-methods study*"<br>Please see last sentence of Abstract, Introduction (no change) |
| Abstract:<br>In the introduction, you may want to consider focusing more on language around highlighting gaps in services for this population. While you discuss this in the introduction section, it is not clear in your study aim. I would also like to hear more about what you are hoping to highlight from the research. For example, you are looking for gaps in access to care and population experience of care, etc. | Thank you for these comments and reflections. We have tweaked the wording of the final sentence of the introduction, to clarify that we are aiming to gather evidence that may be used to improve primary care provision. Due to limitations on word count, we do not have space to provide examples here, however in the study methods the type of evidence being gathered is detailed (e.g., prescribing practice and qualitative exploration of experiences of 'what works' and 'what is needed'). | Abstract introduction, slight word change:<br>*This mixed-methods study aims to enhance the evidence-base provide evidence that may be used to improve primary care services for young people aged 16-25 years with ADHD.* |
| For all study methods, you outlined some basic timelines, | Thank you. Due to the PPIE and stakeholder informed nature of this | NA |

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| but I think you could have been more concrete on your implementation timeline. When do you plan on your study actually taking place? You could also be more specific on identification of participants. | mixed methods study, we have only been able to outline basic timelines. At each stage, there is a reflexive consultation with our research advisory groups which may lead to changes and refinements. Being too prescriptive at the protocol design stage prevents genuine flexibility when involving people with lived experience in delivery of research.<br>In terms of identification of participants, this is also noted. As these are details used in our ethical approval, we will not make changes here, however the comment is noted for the write-up of future project related publications. In addition, it is worth noting that similar to our response above, we have deliberately built flexibility into the plan for identification of participants as we needed our ethical approval to cover a flexible approach suitable for working with people with ADHD. This flexibility also allows us to learn from and adopt processes suggested by our research advisory groups, made up of people with lived experience and clinicians. | |
| You did an excellent job of highlighting the aim of each study method, but these do not seem synthesized accurately when you are talking about the study as a whole. | Thank you for this comment and observation. We are pleased that the aim of each work package is clear. As summarised under Rationale, our overall aim is to:<br>*"… map current services and provide an evidence-base to inform co-produced guidance to improve primary care for young people aged 16-25 years with ADHD*."<br>We do understand that while building an evidence base and co-producing guidance are important first steps to improving care, these will require future work to embed change. Perhaps this discrepancy is why the separate study aims do not seem to synthesise well into the overall aim. Please see our response to your comment below for further thoughts. | NA |

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| You talk in a few points about improving access to care for this population, but you do not seem to be doing that with this study. Rather, you seem to be highlighting gaps (or strengths) in care (which is very important to identify). It seems that a future study or services might actually be focusing on improving access to care. | Thank you for this comment. This is insightful and picks up a tension that perhaps comes through in the protocol. While the ultimate aim of this research is to improve access to care, these specific study activities are about understanding and evidencing current care, (an essential first step) then co-producing guidelines aimed at improving access.<br>As you suggest in future work, we will be more directly aiming to build on this evidence to improve access to care. | NA |
| Some references are older, so you might consider making sure these are foundational articles or updating. | Thank you for this observation. As this protocol is the one approved by our ethics committee, we will not make changes here, but will ensure we review and update for related future publications. | NA |
| Reviewer: 3<br>Dr. Heidi Phillips, Swansea University | | |
| Thank you for asking me to comment on the protocol for the above study. It appears as though the study itself is well underway at the time of my response, based on the dates included in the protocol. I attach my commentary on each of the workstreams in the attached file. | Thank you for your review and for your commentary (which we comment on in the attached document). Your thoughts and reflections on the research are valuable and we will carefully consider these. As noted by the editor, we are unable to make content changes at this stage due to this protocol being approved by our ethics committee. Also, as you have noted, the study is under way. However, your insights, including in reference to UK/Worldwide citations of prevalence, clarifying the English focus of the work, and looking at strengths and limitations by work stream will help us to communicate in future publications with more clarity. | NA |
| *Please see the attached report from this reviewer | Please see comments on the attached report. | See attached document. |

## VERSION 2 – REVIEW

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| **REVIEWER** | Haskell, Brittany<br>Vanderbilt University, School of Nursing |
| **REVIEW RETURNED** | 02-May-2023 |

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| **GENERAL COMMENTS** | Thank you! I still think the age of the participants needs to be clearly outlined in the manuscript. "Young people" could mean young adults, adolescents, or children. Consider specific language in the manuscript to address the age you are targeting. |

## VERSION 2 – AUTHOR RESPONSE

| Reviewer: 2<br>Dr. Brittany Haskell, Vanderbilt University | | |
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| Comments to the Author: | | |
| Comments to the Author:<br>Thank you! I still think the age of the participants needs to be clearly outlined in the manuscript. "Young people" could mean young adults, adolescents, or children. Consider specific language in the manuscript to address the age you are targeting. | Thank you. It is difficult (and wordy) to list the specific words adults/adolescent/children, and as you rightly observe this can create confusion over the age range we are focussed on.<br>We have now added the target age range of 16-25 into the title for this research. This frames the whole article and should address this issue.<br>We had previously specified the age range in several places…<br>Intro - ADHD service provision – young people as aged 16-25 years. (p4)<br>Rationale - aim of research relating to young people added 16-25.<br>We will add in another age specification above this.<br>However, we believe the addition of age range to the article title may be the most | Added to title:<br>(aged 16-25)<br>Added to Rational<br>“aged 16-25” |

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| | helpful way to clarify this. If the editor disagrees, please let us know. | |