

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Involving adolescents in the design, implementation, evaluation, and dissemination of health research: an umbrella review protocol
AUTHORS	Warraitch, Azza; Bruce, Delali; Lee, Maria; Curran, Paul; Khraisha, Qusai; Hadfield, Kristin

VERSION 1 – REVIEW

REVIEWER	Brady, Louca-Mai University of Hertfordshire
REVIEW RETURNED	24-Nov-2022

GENERAL COMMENTS	<p>This is a well-written article outlining a clear and comprehensive plan for an umbrella review. The methodology is sound and I think that this review will be a useful addition to the literature. The public involvement element is also well thought-out and thorough. A paper on how this works out in practice, co-authored by young people involved and following the GRIPP2 guidance would be a really useful output.</p> <p>My queries are mainly around scope: The rationale for the 10-24 age range is not clearly justified, nor whether reviews which overlap this will be included or excluded. A clearer definition of involvement is needed - there is some discussion about the involvement of young people at different stages of the research and brief mention of models of involvement. More discussion is needed of different levels and types of involvement including young co-applicants, co-production, peer research etc with reference to underpinning theory. The review appears to be based on an approach in which young people are consulted in adult-led research. If that is the scope, or if it is not, would be helpful to clarify. Similarly there is a literature on young people's involvement/participation beyond health research which could usefully inform this review, as many of the guidelines and principles of meaningful and effective involvement of young people are transdisciplinary and/or transferrable.</p> <p>The aim of the review is to inform a "set of comprehensive guidelines based on consolidated evidence on youth involvement in health research" but I would be interested to know how the authors will draw on existing guidelines, which tend to be in the grey literature and may not be picked up by this review.</p> <p>If any of these issues are deemed to be out of scope they could be discussed in limitations.</p>
-------------------------	---

REVIEWER	Preston, Jennifer Univeristy of Liverpool
REVIEW RETURNED	29-Nov-2022

GENERAL COMMENTS	Really well-written protocol, and very clear in terms of its objectives and outcomes. The outputs from this review will be invaluable to those working with children and young people in child health research.
-------------------------	---

REVIEWER	<p>Webb, Marianne Orygen The National Centre of Excellence in Youth Mental Health</p> <p>Last year I was invited by the lead author to submit an abstract for a conference symposium in March 2023. The abstract was accepted, however I will not be attending. I have no other working relationship with this author (or any of the other authors)</p>
REVIEW RETURNED	23-Jan-2023

GENERAL COMMENTS	<p>General comments =====</p> <p>This paper reports on the protocol for an umbrella review (review of reviews) investigating how to involve young people in health research. This is a generally comprehensive and well-written protocol. With the increasing interest and commitment to involve young people in health research, this is a timely and needed review.</p> <p>Specific comments =====</p> <p>Major comments -----</p> <ol style="list-style-type: none"> 1. The introduction provides an excellent overview of the topic, highlighting the range of benefits and challenges of involving young people in health research. However, it's not clear what advantages guidelines that cover health research broadly might have over existing guidelines that are more specific in scope. I noted that you make a reference to other articles that may refer to the advantages in the Discussion (top of p.17). More detail is required in the introduction, given this is one of the major rationales for the proposed review. 2. The proposed grey literature search strategy is broad, but a little more detail would be helpful. In particular: <ol style="list-style-type: none"> a. The google search for youth health organisations in low- and middle- income does not have sufficient detail. For example, which countries? How will you define and identify these low- and middle-income countries? Why will only one organisation per country be selected? b. Will one author be responsible for the grey literature searches? c. How will you assess the quality of any grey literature included? d. Are the journals listed non-academic, non-peer reviewed journals? Otherwise, wouldn't these reviews likely be found in the database searches? e. With any Google searches will you need to ensure the search is not geo-targeted to where the searcher is located (i.e., limited to the showing the closest results). <p>Minor comments -----</p> <ol style="list-style-type: none"> 3. In the abstract, you state that dissemination will include participatory workshops, but I don't think they are described at all in the article, or is this reference to the advisory group's role in interpreting results? 4. Describe acronym NHS when first used (p.5). 5. In Grey Literature search, briefly describe what the 'Mental Health Innovation Network' is, and why it may be an appropriate database.
-------------------------	---

	<p>6. Regarding Patient and Public Involvement: Will the young people involved have previous experience of being involved in research? Did young people contribute to the protocol? E.g., search terms.</p> <p>7. Who will conduct the narrative synthesis. One author?</p> <p>8. You state that the themes from the narrative synthesis will be centred around the research questions. However, the research questions aren't stated in the paper (just the research aims).</p> <p>9. In the data extraction, you mention using kappa for inter-relater reliability – but it's not clear exactly how you will do this, given the expected heterogeneity of the data.</p> <p>10. Will you include a study flow diagram to describe the screening and study selection process (for both peer reviewed and grey literature searches)?</p>
--	---

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1 Louca-Mai Brady, University of Hertfordshire	
<p>Comments to the Author:</p> <p>This is a well-written article outlining a clear and comprehensive plan for an umbrella review. The methodology is sound and I think that this review will be a useful addition to the literature. The public involvement element is also well thought-out and thorough. A paper on how this works out in practice, co-authored by young people involved and following the GRIPP2 guidance would be a really useful output.</p>	<p>We thank the reviewer for their very helpful feedback on this protocol. As suggested by the reviewer, we intend to evaluate the involvement of young people in this study and will disseminate the findings in the form of a peer-reviewed article following the GRIPP2 guidelines. All the publications arising from this project will be co-authored with the young people who contribute to this study as co-researchers.</p>
<p>My queries are mainly around scope:</p> <p>The rationale for the 10-24 age range is not clearly justified, nor whether reviews which overlap this will be included or excluded.</p>	<p>This umbrella review is being conducted to inform the development of guidelines on youth involvement in health research. These guidelines focus on adolescents aged 10-24 for the following reasons.</p> <ol style="list-style-type: none"> 1. Wilson et al (2020) conducted a rapid review of the literature on youth involvement and found that there is a lack of a comprehensive set of guidelines on youth involvement in health research for young people aged 10-24. Our overall project aims to <i>address this gap</i> by developing a set of comprehensive guidelines to involve youth aged 10-24 based on the findings of this umbrella review, a rapid review that consolidates the recommendations from the currently available guidelines, and a Delphi study that will establish expert consensus on the best practices of youth involvement in health research. 2. We decided to focus on the involvement of adolescents aged 10-24 years (Sawyer et al., 2021) because there may be differences in the

	<p>recommendations and activities used to engage adolescents and children based on their developmental stage and abilities.</p> <p>3. This project is constrained by limited time and resources and incorporating recommendations for children in the guidelines would increase the workload and prolong the timeline. Therefore, child engagement is beyond the scope of these guidelines.</p> <p>Age range (Adolescents aged 10-24) as an eligibility criteria Reviews that include studies with a sample within the age range of 10 to 24 years will be eligible for inclusion. If the age range of a given review is broader than this—for instance, if a review includes studies with young people aged 5 to 25 years—we will only include the subset of studies from that review whose participants are aged between 10 and 24 years. This is in line with the Cochrane guidelines, which advise that where a particular review’s research objectives are broader than those of an umbrella review, the umbrella review should only include primary studies from that review that meet its eligibility criteria.</p> <p>How overlap in the age range will be managed in this umbrella review: Reviews that are overlapping in terms of age range will be included, however, overlap in the primary studies included in reviews will be addressed using the procedure described on page 14. This will help ensure that the studies included in multiple reviews are only included once.</p> <p>We have added these details on the rationale for the age range and managing overlap in reviews based on age, in the participants’ section under the eligibility criteria on page 14. We have also added the focus on age range of 10-24 to the limitations of the review on page 20.</p>
<p>A clearer definition of involvement is needed - there is some discussion about the involvement of young people at different stages of the research and brief mention of models of involvement. More discussion is needed of different levels and types of involvement including young co-applicants, co-production, peer research etc with reference to underpinning theory. The review appears to be based on an approach in which young people are consulted in adult-led research. If that is the scope, or if it is not, would be helpful to clarify.</p>	<p>This review focuses on all levels and types of involvement, which we have now clarified in the intervention section on page 15 . We have added more details on models of involvement, as well as levels and types of involvement in the introduction section on page 5 . We could not include the names and definitions of the types of youth involvement that are the focus of this review due to the word limit. However, we intend to discuss more than 40 different types of youth involvement methods that we came across as part of this review in a separate paper.</p>
<p>Similarly there is a literature on young people's involvement/participation beyond health research which could usefully inform this review, as many of the</p>	<p>Thank you, this is a great point. We will include reviews focusing on overall youth engagement as long as these include at least one study on youth involvement in health research in accordance with Cochrane guidelines which advise that where a particular review’s research objectives are</p>

<p>guidelines and principles of meaningful and effective involvement of young people are transdisciplinary and/or transferrable.</p>	<p>broader than those of an umbrella review, the umbrella review should only include primary studies from that review that meet its eligibility criteria. We have clarified this in the intervention section of the eligibility criteria on page 14-15.</p> <p>Although the literature on the overall involvement of young people could have informed the guideline development due to the transdisciplinary nature of the principles, we had to restrict the eligibility criteria to the literature on health research due to time and resource constraints. The literature on overall youth involvement encompasses their involvement in service design, civic engagement, community mobilization, etc and it would not be realistically possible to complete the guideline development process within the project timeline if we also reviewed the literature on overall youth involvement. We have now indicated that this is a limitation of the review on page 20.</p>
<p>The aim of the review is to inform a "set of comprehensive guidelines based on consolidated evidence on youth involvement in health research" but I would be interested to know how the authors will draw on existing guidelines, which tend to be in the grey literature and may not be picked up by this review.</p>	<p>Thank you, this is a great question. The guideline development process involves the following four phases.</p> <ol style="list-style-type: none"> 1. This umbrella review to consolidate the literature on youth involvement in health research 2. A rapid review to identify the currently available guidelines in health research, to extract the recommendations from these, compare and contrast the included recommendations with the findings from the umbrella review, identify the gaps in the evidence and the recommendations included in the guidelines 3. A mixed-method Delphi study with 30 researchers, 30 young people aged 10-17, and 30 young people aged 18- 24 years will be conducted to address the gaps in the evidence consolidated using the umbrella review and the gaps in the recommendations included in the currently available guidelines identified from the rapid review 4. Translate the evidence from these three sources into a new set of guidelines with a panel of researchers and young people aged 10-24 years. <p>Hence, we will draw on the existing guidelines in the rapid review, not this umbrella review. This rapid review has been pre-registered with (PROSPERO #CRD42021293586) and has a very comprehensive grey literature search strategy, similar to this umbrella review, to ensure we identify all the relevant guidelines that are currently available on the involvement of young people in health research. We have added a sentence on page 8 to clarify this.</p>
<p>If any of these issues are deemed to be out of scope they could be discussed in limitations.</p>	<p>Thank you. We have added the age range and the exclusive focus on youth involvement in health research to the limitations of the review on page 20.</p>
<p>Reviewer: 2 Dr. Jennifer Preston, University of</p>	

Liverpool	
<p>Comments to the Author: Really well-written protocol, and very clear in terms of its objectives and outcomes. The outputs from this review will be invaluable to those working with children and young people in child health research.</p>	<p>We thank the reviewer for their very positive evaluation of the protocol.</p>
<p>Reviewer: 3 Dr. Marianne Webb, Orygen, The National Centre of Excellence in Youth Mental Health, The University of Melbourne Centre for Youth Mental Health</p>	
<p>Comments to the Author: General comments =====</p> <p>This paper reports on the protocol for an umbrella review (review of reviews) investigating how to involve young people in health research. This is a generally comprehensive and well-written protocol. With the increasing interest and commitment to involve young people in health research, this is a timely and needed review.</p>	<p>We thank the reviewer for their positive evaluation of the protocol and very helpful feedback and comments.</p>
<p>1. The introduction provides an excellent overview of the topic, highlighting the range of benefits and challenges of involving young people in health research. However, it's not clear what advantages guidelines that cover health research broadly might have over existing guidelines that are more specific in scope. I noted that you make a reference to other articles that may refer to the advantages in the Discussion (top of p.17). More detail is required in the introduction, given this is one of the major rationales for the proposed review.</p>	<p>Thank you for highlighting this. We have added a paragraph on page 8 to indicate why there is a need for a comprehensive set of guidelines and the usefulness of these guidelines over topic or subject-specific guidelines.</p>
<p>2. The proposed grey literature search strategy is broad, but a little more detail would be helpful. In particular:</p> <p>a. The google search for youth health organisations in low- and middle- income does not have sufficient detail. For example, which countries? How will you define and identify these low- and middle-income countries? Why will only one organisation per country be selected?</p>	<p>a. We will use the world bank's classification of countries to define low and middle-income countries. Since the initial google search will be limited to 20 pages, we will conduct an additional google search for youth health organizations in each of the 137 low and middle-income countries individually to ensure the inclusion of the most relevant organizations from LMICs. We will only include organizations that show up as the top result to manage the workload as even with just one organization, 137 organizations will be included. Note that this search was conducted in addition to the overall google search for youth health organizations, the MHIN database search, and inclusion of organizations known to the authors. We have added these details on pages 11-12 of the</p>

<p>b. Will one author be responsible for the grey literature searches?</p> <p>c. How will you assess the quality of any grey literature included?</p> <p>d. Are the journals listed non-academic, non-peer reviewed journals? Otherwise, wouldn't these reviews likely be found in the database searches?</p> <p>e. With any Google searches will you need to ensure the search is not geo-targeted to where the searcher is located (i.e., limited to the showing the closest results).</p>	<p>manuscript.</p> <p>b. Yes, one author (AW) will be responsible for all grey literature searches. We have indicated this on page 13.</p> <p>c. The quality of all included systematic reviews will be assessed with a MeaSurement Tool to Assess systematic Reviews-2 (AMSTAR 2), irrespective of whether these are peer-reviewed or grey literature. We have expanded discussion of the risk of bias assessment method on page 18 of the manuscript.</p> <p>d. These journals are peer-reviewed and the reviews should ideally be found in the database searches. However, searching individual journals will make the search strategy more rigorous and will minimise the risk of missing relevant reviews.</p> <p>e. Unfortunately, we didn't address geo-targeting while performing the google searches. However, the inclusion of a wide range of search sources and methods may have potentially addressed the issue of geo-targeted results. We will describe this as a limitation in the published review.</p>
<p>Minor comments</p>	<p>-</p>
<p>3. In the abstract, you state that dissemination will include participatory workshops, but I don't think they are described at all in the article, or is this reference to the advisory group's role in interpreting results?</p>	<p>Yes, we will conduct participatory workshops to engage the youth advisory group in the interpretation and dissemination of findings. These participatory workshops will be designed in consultation with youth co-researchers and will also be co-facilitated by the youth co-researchers. In the first participatory workshop, the youth advisory group will be presented with the findings of the review and will be asked to share their interpretation of the findings. In the second workshop, the youth advisory group will be asked to review the article/report and to help us disseminate the findings in the form of a blog or social media posts.</p> <p>We have clarified this in the public and patient involvement section on pages 21-22.</p>
<p>4. Describe acronym NHS when first used (p.5).</p>	<p>We have now defined the acronym on page 6.</p>
<p>5. In Grey Literature search, briefly describe what the 'Mental Health Innovation Network' is, and why it may be an appropriate database.</p>	<p>The mental health innovation network is a community of global mental health researchers, health professionals, policymakers, and other relevant stakeholders. MHIN has a database of organizations working to promote health in communities in low, middle, and high-income countries. The MHIN database interface has search options for organizations based on the target population that they work with and the countries. We decided to include MHIN database because it has records of several youth health organizations registered in low and middle-income countries, which helped ensure inclusion of the most relevant organizations in LMICs.</p> <p>We have added the description and rationale for including MHIN on pages 11-12.</p>
<p>6. Regarding Patient and Public Involvement: Will the young people involved have previous experience of being involved in research? Did</p>	<p>Previous experience of being involved in research was not a criterion for young people to be involved in research. The youth co-researchers DB, ML, and PC reviewed the protocol and gave their feedback; however, the protocol was designed</p>

young people contribute to the protocol? E.g., search terms.	<p>before the youth co-researchers joined the team and they did not have any role in the development of the search strategy or design of the protocol. It is a limitation of the public and patient involvement in this review that we could not recruit youth co-researchers in time to seek their input at the design stage.</p> <p>We have elaborated on the public and patient involvement section on page 19 to include these details.</p>
7. Who will conduct the narrative synthesis. One author?	The narrative synthesis will be conducted by the lead author AW and a youth co-researcher ML. This will involve both authors analysing a subset of the data together until there is a general agreement on the coding and narrative building. We have added these details to the section on narrative synthesis on page 21.
8. You state that the themes from the narrative synthesis will be centred around the research questions. However, the research questions aren't stated in the paper (just the research aims).	We have corrected this on page 18 to state the narrative synthesis will be centered around the research aims.
9. In the data extraction, you mention using kappa for inter-rater reliability – but it's not clear exactly how you will do this, given the expected heterogeneity of the data.	<p>Establishing the inter-rater reliability will be specific to the data extraction fields that have close-ended responses and risk of bias assessment. For open-ended data extraction fields, AW will compare the data extracted by all reviewers to assess whether a general agreement has been established in the data extraction process.</p> <p>We have added these details to the data extraction section on page 17.</p>
10. Will you include a study flow diagram to describe the screening and study selection process (for both peer reviewed and grey literature searches)?	<p>Yes, this umbrella review will be reported as per the PRISMA statement and that requires including a flow chart to describe the search, screening and study selection process for both peer reviewed and grey literature searches individually.</p> <p>We have added a sentence to indicate this on page 16.</p>

VERSION 2 – REVIEW

REVIEWER	Brady, Louca-Mai University of Hertfordshire
REVIEW RETURNED	13-Apr-2023
GENERAL COMMENTS	I am satisfied that the authors have addressed all the points made in my initial review, and have done so thoughtfully and thoroughly.