Systematic Reviews

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Involving adolescents in evidence syntheses: an umbrella review

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Abstract

Background Stakeholder involvement in evidence syntheses has the potential to enhance the quality and relevance of reviews. However, adolescents rarely participate in evidence synthesis, mainly because their role and influence in shaping the synthesis process relating to health outcomes are poorly understood. To fully unlock the potential of evidence syntheses for adolescent health, it is crucial to understand how adolescents can contribute at various stages of the review process and how their involvement can influence outcomes.

Methods To achieve this, we conducted an umbrella review examining adolescent involvement in reviews related to adolescent health research, complemented by a case study that highlights how adolescents were engaged at various stages of this review. We ran a search across 11 databases, screened reference lists and 12 journals, and consulted experts in youth involvement.

Results We found only 10 reviews which involved adolescents. In those reviews, adolescents were engaged at almost every stage of the review process, with most involvement centred around interpreting findings or co-authoring the final reports. While adolescent participation was often consultative, there were examples of more collaborative involvement using a wide range of methods, even at technical stages like study selection and data analysis. However, reviews did not report on the impacts or benefits of adolescent involvement in evidence syntheses.

Conclusion To maximise the impact of adolescent involvement, we call for engagement of adolescents throughout the review process and the adoption of frameworks to ensure transparency and consistency in reporting.

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Keywords Adolescent involvement, Participatory research, Youth engagement, Evidence syntheses methods

Introduction

Over the past two decades, there has been an increased demand for adolescent involvement in research [1]. Adolescents are defined as those aged 10 to 24 years as per the conceptualisation of adolescence by Sawyer and colleagues [2]. Adolescent involvement is "research that is done 'with' or 'by' young people, not 'to', 'about', or 'for' them" [3, 4]. This approach aligns with Article 12 of the UN Convention on the Rights of the Child (UNCRC), which states that young people have the right to participate in decisions affecting them, including in research and the design of services [5]. A wealth of evidence indicates the benefits of adolescent involvement in research [6]. For adolescents, active involvement in research may build their skills and knowledge [7, 8], can support their academic and career development by building their resumes [9], may strengthen their relationships [10],

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and can contribute to their personal growth [11]. For the research itself, adolescent involvement can ensure the study is more relevant to the needs of adolescents [4], may improve recruitment and data collection processes [12, 13], can increase the rigour of data analysis [14], and holds the potential to broaden the dissemination of findings [15]. Additionally, adolescent involvement may result in researchers gaining valuable insights and skills related to effectively engaging with adolescents throughout the research process [8, 11].

Beyond empirical research, adolescents can also contribute to secondary research, particularly in evidence syntheses [16]. The significance of overall stakeholder involvement in evidence syntheses is well established, with multiple case studies demonstrating how stakeholders can be successfully involved in systematic reviews [17–21]. Stakeholder involvement holds the potential to address the barriers to uptake of evidence synthesis findings into practice [21]. This recognition of the benefits of stakeholder involvement in evidence synthesis has led to the development of frameworks [22] and guidance on involving the public at various stages of the review process [23–25].

However, adolescents are less frequently involved in conducting evidence syntheses compared to other stakeholders [26]. This was highlighted in a study exploring consumer involvement practices, where interviews were conducted with key informants from seven internationally renowned organisations that focus on commissioning and conducting reviews and involving consumers in their reviews. These interviews revealed that various types of stakeholders and consumers were being involved in evidence syntheses at their organisations, but children and adolescents were notably absent from the review processes at all of these organisations [24]. Similarly, in reviews exploring overall public and patient involvement (PPI) in evidence syntheses, only a few examples of adolescent involvement have been identified. The most comprehensive analysis of overall stakeholder involvement in different types of reviews, conducted by Pollock and colleagues, identified a total of 291 reviews [21]. Of these, only eight reviews, less than 3% of those involving overall stakeholders, engaged young people. This stands in contrast to the more frequent involvement of adult stakeholders in conducting evidence syntheses. Furthermore, the current guidance on consumer or stakeholder involvement in systematic reviews is primarily focused on adults, underscoring the lack of emphasis on adolescent involvement [23–25]. The prioritisation of adult involvement in evidence syntheses reflects a deeper issue of adultism, the belief that adults are inherently more knowledgeable, capable, or valuable than young people [27]. This belief often limits adolescents' involvement in decisions that impact them, placing them at a disadvantage compared to adult stakeholders.

To address adultism in evidence synthesis practices and to promote adolescent involvement, it is crucial to understand how adolescents can actively contribute to evidence syntheses and how their involvement impacts them and the review process. We conducted an umbrella review to consolidate evidence on the following: (i) the methods used to involve adolescents at different stages of the evidence synthesis process, (ii) the challenges and facilitators affecting adolescent involvement in evidence syntheses, (iii) the impacts of adolescent involvement on both the review and the adolescents themselves, and (iv) the best practices for involving adolescents in evidence syntheses. Additionally, this paper describes the methods used to engage adolescent co-researchers and advisors at different stages of this umbrella review, demonstrating how adolescents can be successfully involved throughout the evidence synthesis process.

Methodology

This umbrella review was conducted following the Cochrane guidelines for overviews of reviews [28], with some adaptations, such as the types of reviews included, to better align with the review's objectives. The review was registered with the International Prospective Register of Systematic Reviews (CRD42021287467), and any methodological changes were preregistered in the updated PROSPERO record. This paper is based on a subset of reviews from a broader umbrella review that aimed to consolidate all review-level literature on adolescent involvement in health research. The broader umbrella review identified 99 eligible reviews on this topic. In this paper, we focus on a subset of these 99 reviews that involved adolescents in the process of designing, conducting, or disseminating evidence syntheses on adolescent involvement in health research. A detailed description of the methods used for the broader umbrella review can be found in the published protocol paper [29].

Search strategy

The search strategy for this umbrella review focused on adolescents aged 10–24 years, adolescent involvement in health research, and the review type (including various review formats such as scoping, systematic reviews, and meta-analyses), using Boolean operators to combine terms. Authors A. W. and K. H. collaborated with a research librarian (G. F.) from Trinity College Dublin to develop the search strategy. The detailed search strategy is provided on the OSF page of the review (https://osf.io/cx7y9/?view_only=4f40ba5530f64c608c405ce66a4a7243).

Information sources for peer-reviewed and grey literature search

We searched the Cochrane Database of Systematic Reviews, MEDLINE, Scopus, Embase, PsycINFO, PsycArticles, CINAHL, Epistemonikos, and Health Systems Evidence, to identify relevant reviews. The grey literature search involved multiple components. A simplified search strategy with fewer key terms was applied to Google Scholar, limited to the first 10 pages of results. The top 10 paediatric, perinatology, and child health journals from the Scimago Journal and Country Rank list were reviewed using a similar simplified strategy. Conference abstracts, theses, reports, and unpublished reviews were identified through Web of Science and ProQuest searches, with strategy adapted to each database's interface. Reviews registered on PROSPERO were also searched, and review authors were contacted to share data from reviews close to or recently completed. A targeted search of websites from relevant organisations focused on adolescent health (including government, nonprofits, and health organisations) was conducted within Google and the Mental Health Innovation Network database. Additionally, a search for youth health organisations in low- and middle-income countries was conducted, focusing on the top results for each of the 137 countries using World Bank classifications. A simplified search strategy was used for organisational websites, and experts in youth involvement in health research were contacted for potentially relevant materials. Reference lists from eligible reviews were screened, and the Connected Papers software was used to identify similar papers.

Since these sources were searched in December 2021, we updated our search by screening the list of reviews included in another umbrella review on youth involvement in health research, published in 2024, to identify further relevant reviews [30]. Additionally, we conducted a hand search of the volumes published from 2021 to 2024 of two journals focused on public and patient involvement in health research: *Health Expectations* and *Research Involvement and Engagement*. We systematically reviewed each issue of these journals, screening titles, abstracts, and keywords to identify articles relevant to our inclusion criteria. Full texts of potentially relevant articles were examined to determine their inclusion in our updated review.

Eligibility criteria

This specific subset of the umbrella review included various types of reviews to capture a range of qualitative outcomes related to adolescent involvement in evidence syntheses. This included narrative reviews, targeted reviews, rapid reviews, scoping reviews, literature reviews, qualitative reviews, integrated reviews, evidence maps, critical reviews, desk reviews, mixed-methods reviews, overviews, state-of-the-art reviews, practitioner reviews, systematic reviews, and meta-analyses. We used the categorisation and definition of reviews provided by the authors, either in the published article or through personal correspondence. Only reviews focusing on adolescents aged 10–24 were included, with flexibility for reviews that did not specify exact age ranges but focused on children and adolescents.

While the broader umbrella review included reviews exploring adolescent involvement in health research, this specific paper included a subset of reviews that explored adolescent involvement in evidence syntheses related to their involvement in health research and reported on at least one of the following outcomes: the stages at which adolescents were involved in the review process, the methods used to involve adolescents, the impacts of their involvement, and the challenges and facilitators of their involvement. Only reviews published in English were included.

Selection of studies

Search results from the electronic databases were imported into Covidence to remove duplicates. For the broader umbrella review, A. W. handled the title and abstract screening for all articles, while the co-researchers screened 25% to reduce bias. For full-text screening and data extraction, A. W. screened all articles, while co-researchers reviewed 10% to ensure accuracy. Any disagreements were settled through discussions among the team, and if needed, a fourth researcher was consulted (Fig. 1). To assess the reliability of the screening process, we calculated Cohen's kappa values, which indicated substantial agreement beyond chance, 0.83 at the title and abstract screening stage, and 0.68 at the full-text screening stage. While full double screening could have further enhanced rigour, the high agreement rates suggest that the single-reviewer approach did not compromise the reliability of study selection.

Risk-of-bias assessment

A MeaSurement Tool to Assess Systematic Reviews (AMSTAR) [31] was used to evaluate the methodological quality of systematic reviews included in the broader umbrella review. However, a risk-of-bias assessment was not conducted for the subset of reviews in this paper as this paper aimed to synthesise how adolescents were engaged in evidence syntheses rather than make conclusions about the validity of the findings of the included reviews. Including this risk-of-bias assessment could have introduced an unnecessary layer of exclusion or

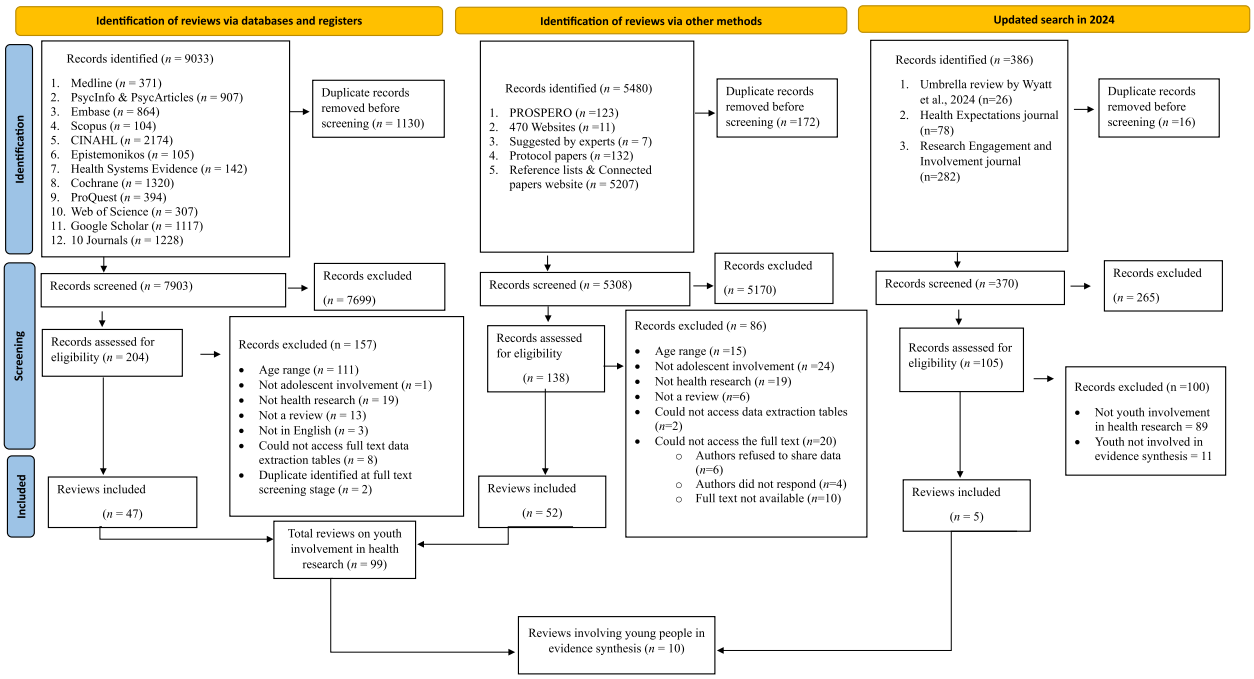

Fig. 1 PRIOR flow chart

interpretation that was beyond the scope of this analysis. Instead, this paper prioritises transparency in reporting the nature and impact of adolescent involvement across various types of reviews, regardless of methodological rigour.

Data extraction and synthesis

Data for this paper from a subset of reviews included in the broader umbrella review was extracted in Excel by a young co-researcher (M. S.) and checked by A. W. Data was extracted on the area of health research, countries where adolescents were involved, type of review, characteristics of adolescents, aim of involvement, stage of the review process, level of involvement, methods used, challenges faced, facilitators, compensation provided, benefits of involvement for adolescents, the impacts of involvement on the review, and best practices identified. Involvement at different stages of the review process was categorised using the 11 stages of a review outlined by the Cochrane Review Ecosystem [32]. The methods of involvement included approaches used to involve adolescents at different stages of the evidence synthesis process such as participatory workshops, meetings, or advisory group discussions. Challenges were defined as factors hindering adolescent involvement or limiting their participation, while facilitators referred to elements that enhanced or enabled their engagement. Benefits of involvement for adolescents were defined as positive outcomes of involvement in the evidence synthesis process. Impacts of involvement on the evidence syntheses referred to improvement in the quality, relevance, accessibility, inclusiveness, or reach of the review. Best practices were strategies for effective adolescent involvement in evidence syntheses.

We extracted all qualitative details reported in the included reviews for the extraction fields outlined above and only categorised extraction for the level of involvement field. The level of involvement was categorised according to the model of children and young people's involvement in research by Shaw and Brady [33], which describes four levels of adolescent involvement in research, ranging from participation as research subjects to full ownership of the research process by children and young people. To assign these levels, we extracted data from included reviews on how adolescents' input was sought and incorporated into the evidence synthesis process. Consultation with adolescents was defined as young people sharing their perspectives and feedback with adult researchers in the evidence synthesis process, who then consider these inputs when making decisions about the research. However, decision-making power remains predominantly with the adult research team. As collaborators, young people share decision-making power with adult researchers across multiple or all stages of the evidence synthesis process. This collaborative approach involves young people actively contributing to tasks such

Table 1 Demographic characteristics of adolescent coresearchers

Initials	Role in the project	Gender	Age	Education	Country of residence
DB	Screened articles at title and abstract screening and full-text screening stages	Female	18	High school student	USA
PC	Extracted data from reviews	Male	23	Masters in psychology student	Ireland
ML	Extracted data from reviews, contributed to narrative synthesis, co-authored four manuscripts, and presented review findings at a departmental seminar	Female	22	Undergraduate psychology student	Ireland
SB	Contributed to the write-up of the introduction and methods section of a paper as a co-author	Female	23	Masters in social work student	Ireland
CW	Designed and co-facilitated the participatory workshop with adolescents, contributed to write-up of the introduction and methods section of a paper as a co-author, co-authored three papers, and presented findings from the participatory workshop at a departmental seminar	Female	20	Undergraduate psychology student	Ireland
JH	Co-designed and co-facilitated a workshop to interpret the findings from the umbrella review with an adolescent advisory group	Male	20	Undergraduate psychology student	Ireland

as planning and designing the evidence synthesis, conducting screening and data extraction, analysing data, and disseminating study findings. As co-researchers, young people share ownership over the research process, they take leadership roles and make key decisions about the study, supported by guidance and expertise from researchers. A. W. and M. S. reviewed and discussed the categorisation of levels of involvement based on the description of the involvement process in the reviews to minimise the risk of bias and subjectivity in interpretation.

A structured narrative synthesis was conducted by A. W. The process began with familiarisation with the extracted data, followed by deductive coding based on predefined categories such as the stage of the review process, level of adolescent involvement, engagement methods, challenges, and reported impacts. Rather than developing emergent themes, findings were descriptively organised into pre-structured categories aligned with Cochrane's Review Ecosystem [32].

Adolescent involvement in this umbrella review

Recruitment of adolescents

Five adolescent co-researchers (M. L., P. C., C. W., J. H., S. B.) were recruited through Trinity College Dublin's undergraduate and master's courses in psychology. One adolescent co-researcher was a high school student from the USA (D. B.) (Table 1). We recruited the members for the adolescent advisory group through an Irish youth health organisation SpunOut and through snowball sampling with assistance of a colleague in Kenya. Adolescent advisory group members ($n=12$) were recruited from Ireland and Kenya for convenience, as we had existing connections with organisations and adolescents in these countries. Additionally, this choice ensured equal representation of adolescent advisors from a high-income and a lower-middle-income country.

Training

We provided initial training to adolescent co-researchers to familiarise them with the project's objectives, the review process, and their specific roles. In these training sessions, they were provided with an introduction to the umbrella review methodology, key terminology, and step-by-step practical demonstrations of the tasks on which they wanted to work. For instance, we trained D. B. on the screening process, including how to apply inclusion and exclusion criteria at title and abstract and full-text screening stages. We provided her with hands-on practice sessions using sample articles to build her familiarity with the criteria. Similarly, we trained D. B., M. L., and P. C. on data extraction by demonstrating how to accurately identify and record relevant information from the included guidelines. We gave them an overview of the Covidence software and Excel used for the review and provided them with step-by-step guidance on navigating these. We held regular check-ins and feedback sessions with them to review the work together, address any questions, and provide additional guidance as needed.

Writing and publishing the protocol

We involved three adolescent co-researchers (D. B., M. L., P. C.) in reviewing the initial draft of the protocol paper [29]. The co-researchers received training on the basics of research protocols, to familiarise them with what a research protocol includes, its purpose, and the key sections. Co-researchers were given the protocol draft to review individually and were encouraged

to annotate sections they found unclear and to provide suggestions for improvement. After the individual review, the co-researchers participated in one-on-one discussions with the lead author (A. W.), who explored the rationale behind their suggestions. Co-researchers flagged areas where the protocol's language was too technical or inaccessible. They recommended using simpler, more youth-friendly alternatives to technical terms and suggested changes to improve grammatical accuracy. In instances where feedback could not be fully incorporated, A. W. explained the reasoning behind this to the co-researchers.

Study selection

In conducting this umbrella review, we involved a young co-researcher (D. B.) in two levels of article screening: the title and abstract screening and the full-text screening. She was provided with brief training, focusing on an overview of the umbrella review methodology using the Cochrane guidelines for overviews of reviews [28], how to assess studies based on titles and abstracts, applying eligibility criteria at the full text stage, and how to document the reasons for exclusion. She also received guidance on using Covidence, the review management software, and how to use its different features. She was provided with a detailed document outlining the eligibility criteria, which were discussed in training sessions to ensure clarity and consistency in applying these. Furthermore, A. W. conducted mock screening sessions with D. B., allowing her to practice decision-making and receive feedback. This helped familiarise her with the types of articles she would screen during the review process. The co-researcher (D. B.) then independently screened 25% of the articles at the title and abstract stage and 10% at the full-text screening stage. In cases where there were discrepancies between two reviewers' decisions on article inclusion or exclusion, consensus meetings were held to resolve any differences. D. B.'s insights often led to further discussion and, in some cases, the inclusion of articles that might have otherwise been excluded.

Data extraction

In our umbrella review, three adolescent co-researchers (D. B., M. L., P. C.) were involved in extracting relevant data from 10% of the included reviews. During the training sessions, co-researchers were familiarised with data extraction forms and were guided on how to identify and extract the required data. This training ensured they could identify the relevant information in different sections of the papers. Before starting the full extraction process, the co-researchers participated in pilot exercises where they extracted data from a few sample studies and were provided with feedback by A. W. Once trained, co-researchers participated in the data extraction process independently using a standardised template. After completing their extractions, they met with A. W. to discuss the process and address any discrepancies. Throughout the data extraction process, adolescent co-researchers received ongoing support from A. W.

Data analysis and interpretation of findings

In this umbrella review, an adolescent co-researcher (M. L.) contributed to synthesising the findings using the extracted data along with the lead author A. W. She was trained using the narrative synthesis guidance manual [34], on the process of coding, sorting similar codes into categories, and describing these categories. M. L. then helped code data from five reviews using both inductive and deductive coding. After coding individual studies, M. L. met with A. W. to compare their coding and discuss any discrepancies.

Additionally, we conducted a participatory workshop with 12 adolescent advisors to interpret the findings from the included reviews on the challenges adolescents face during their participation in health research. Two adolescent co-researchers (C. W., J. H.) took an active role in planning this participatory workshop. They were provided with two training sessions to orient them to the current umbrella review and its findings, different participatory methods that can be used to engage adolescents in health research, the aims and goals of the workshop, and the importance of creating a space where adolescent advisors felt comfortable sharing their experiences and opinions. Following the training, the co-researchers worked together to outline the workshop's design and proposed the use of different interactive elements (e.g. icebreakers, group activities) and strategies to keep discussions focused on the research questions.

Twelve adolescent advisors, 9 male and 3 female advisors, from both Kenya and Ireland, participated in the workshop. Co-researchers (C. W., J. H.) and the lead researcher (A. W.) facilitated discussions on the reported challenges to adolescent involvement in the review and prompted the group to share any additional barriers and to suggest the mitigation strategies to address the reported barriers. The adolescent advisory group agreed with most of the challenges reported in the review but also shared several additional barriers, which had not been adequately covered in the literature. C. W. and J. H. recorded the discussions using sticky notes and charts, capturing key insights and suggestions in real-time.

After the workshop, co-researchers (C. W., J. H.) helped synthesise the data collected during the workshop. Each suggestion made by adolescent advisors during the workshop was given a unique code. Co-researchers were responsible for assigning these codes and organising

them into broader themes. Once the coding was completed, co-researchers and A. W. aggregated the codes into overarching themes. The findings of this workshop are reported elsewhere [35].

Write-up and dissemination

In this umbrella review, all adolescent co-researchers (D. B., M. L., P. C., C. W., J. H., S. B.) actively contributed to the dissemination of the findings from the review in different forms. C. W. helped organise an online webinar with A. W. aimed at both academic and public audiences. She helped prepare the presentation materials, including slides and talking points, and co-presented the findings from the review on the benefits of adolescent involvement in health research for the adolescents themselves. Some co-researchers also co-presented the findings of the review at the Trinity Centre for Global Health weekly departmental seminars. For example, D. B. co-presented the protocol of the review along with A. W. at one of the departmental seminars held in 2022, while C. W., M. L., and J. H. co-presented the findings on the challenges to adolescent involvement in health research and the findings from the participatory workshop with A. W. at a departmental seminar in 2023.

All co-researchers contributed as co-authors on three papers that resulted from this review. D. B., M. L., and P. C. co-authored the protocol paper by reviewing and refining the paper and ensuring the use of inclusive and accessible language. They also helped draft sections of other papers. For example, M. L. led the writing of the methods section of the paper reporting the challenges to adolescent involvement in health research and is acknowledged as the second author [35]. C. W. and S. B. took the lead on writing the introduction, methods, and results sections of a paper that highlights the positive impacts of adolescent involvement in health research. They also developed illustrations for the paper and were acknowledged as joint first authors alongside A. W. [15].

Results

We identified only 10 reviews for inclusion in this manuscript that examined adolescents' involvement in health research, where adolescents were engaged at one or more stages of the review process (Figs. 1 and 2). The characteristics of the included reviews are summarised below.

Characteristics of included reviews

Most reviews ($n=6$) focused on adolescent involvement in overall health research [1, 4, 36–39]. Two reviews explored health and social sciences [8, 40]: one focused on mental health research [41], and one looked specifically at the involvement of adolescents who had adverse childhood experiences [42]. Four were rapid reviews [4, 8, 39, 40], while two were systematic [38, 41], scoping [1, 36], and narrative reviews [37, 42].

Characteristics of adolescents involved

Most reviews were conducted in the UK ($n=6$) [1, 4, 36, 37, 40, 42]. Two reviews included adolescents from Canada [38, 41], and one review each included adolescents from Ireland [39] and the USA [41]. The number of adolescents involved in reviews depended on their roles. For example, the number of adolescent co-researchers involved ranged from 1 [36, 40, 42] to 3 [41], while the number of adolescent advisors varied from 6 [37] to 27 [1]. Only three reviews reported

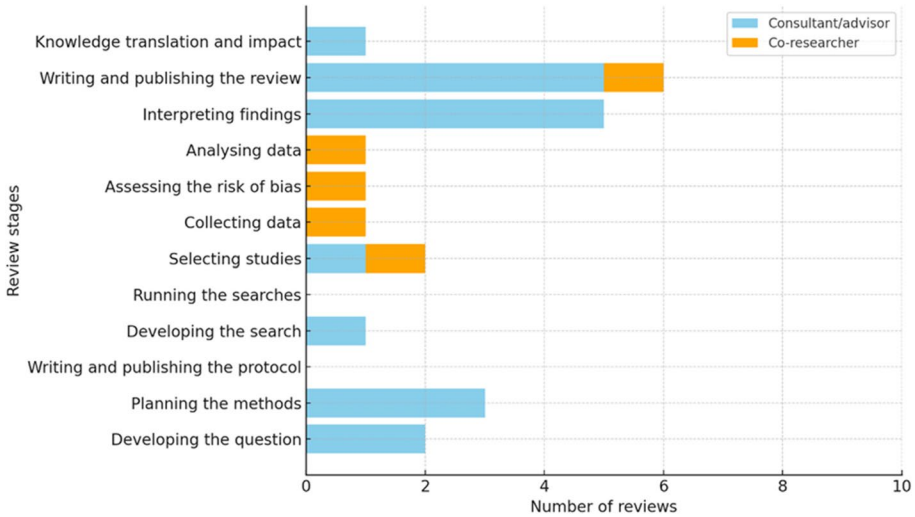

Fig. 2 Level of adolescent involvement at different stages of the evidence synthesis process

the age of the adolescents involved [1, 39, 41], which ranged from 12 to 24 years old. Two of these reviews, however, only included adolescents over the age of 18 [39, 41]. Adolescents' genders were reported in five reviews; these reviews all involved only male or female adolescents and young people [36, 39–42]. Six reviews provided details on the background of adolescents involved. Four reviews engaged adolescents with previous relevant experience. In one review, this experience was related to previous involvement in mental health research [41], while two others focused on individuals with experience receiving services [36, 40]. One review involved adolescents with lived experiences of mental health challenges [1], and two included young students as co-researchers [39, 42].

Level of adolescent involvement at different stages of the review process

We categorised adolescent involvement using the 11 stages of a review outlined by the Cochrane Ecosystem [32]. The level of adolescent involvement at different stages of evidence synthesis process is reported in Fig. 2. Two reviews involved adolescents as co-researchers throughout the entire review process, though specific stages and methods used were not described [38, 42].

Adolescent involvement at different stages in the included reviews

Developing the questions and planning methods

In two reviews, adolescents helped refine the review's scope and questions. For example, Rouncefield-Swales consulted a young service user, leading to a shift in focus towards the impacts of adolescent involvement and specifically to examining the characteristics of those included or excluded from the research process [36]. Larkins and colleagues [8] conducted a weeklong online hackathon with peer researchers from marginalised groups. Through daily creative problem-solving sessions, adolescents contributed to refining core aspects of the review, including the development of research questions, defining key terms, and determining the eligibility criteria. In one review, adolescents' involvement at later stages resulted in the refinement of methods used. Thomas and colleagues [37] reported how adolescents' input as members of a youth advisory group during the interpretation and dissemination stages led to an unexpected but useful revision of the data extraction process. After discussions with adolescents, the team revised their data extraction form to include additional aspects identified by adolescents as important.

Developing the search strategy and running the search in databases

At the search strategy development stage, Larkins and colleagues' [8] hackathon engaged adolescents to contribute directly to the development of the search strategy by brainstorming relevant terms and methods for identifying studies that focused on adolescent involvement in research. None of the reviews reported involvement of adolescents in running the search.

Study selection

In the study selection phase, Warraitch and colleagues [39] involved a young co-researcher in the title and abstract and full-text screening stages. This co-researcher screened 25% of the articles at the title and abstract stage and 10% of the articles at the full-text stage. At this same stage, Wilson and colleagues [4] involved adolescents as consultants by seeking their help to identify relevant studies on adolescent involvement in health research that had been missed during both the database and grey literature searches.

Data extraction

At the data extraction stage, Warraitch and colleagues [39] involved a young co-researcher as a second reviewer for some of the included articles, to ensure data accuracy and consistency.

Data analysis and interpretation of findings

McCabe and colleagues engaged adolescents as co-researchers in reviewing the categories and themes that emerged from the coded data. Adolescents helped refine these categories by merging similar codes under relevant themes, ensuring that their perspectives were accurately reflected in the analysis [41]. In five reviews, adolescents were actively consulted when interpreting the findings, providing a critical layer of reflection on how the results aligned with their lived experiences. For instance, McCabe and colleagues held a consultation meeting with three adolescents, using their input to revise key sections of the study. Their feedback led to the addition of new impacts and challenges, a restructuring of the recommendations section, the inclusion of more specific examples, and revisions in the phrasing of some recommendations. This process ensured that the findings were both relevant and practical from a youth perspective [41]. Similarly, Erwin and team [40] engaged a young person to interpret the review's findings based on her own experiences.

Sellars and colleagues [1] took a similar approach, holding two consultation meetings with youth advisory groups to get input on specific elements of their

review. The first was a 40-min face-to-face session with six adolescents aged 17–18, and the second was a virtual session with 21 adolescents aged 14–17. These consultations focused on visual representations related to youth advisory groups (YAGs), discussing the pros and cons of YAG involvement, providing recommendations for reporting YAG activities, and suggesting preferred methods of acknowledgment and dissemination. These sessions allowed adolescents to influence both the content and presentation of the review's findings. Larkins and colleagues [8] referred to the overlap between the findings of the initial hackathon conducted with adolescents and the findings from the review to highlight the convergences and disagreements in adolescents' perspectives and the findings reported in the studies. While Thomas and team also consulted adolescents during the interpretation stage, the specifics of their involvement were not detailed, pointing to a need for greater transparency in reporting such contributions [37].

Write-up and dissemination

Adolescents played a significant role in the write-up and dissemination stages across several reviews, often contributing as co-authors and co-creators of outputs. For example, McCabe and team involved a young person in developing illustrations, graphs, and writing parts of the paper, ensuring their contributions were recognised in both content development and authorship [41]. Similarly, Erwin and colleagues engaged a young person in interpreting findings through her lived experience, incorporating her reflections and acknowledging her as a co-author [40]. Warraitch and team also involved two young co-researchers in reviewing the manuscript and providing input, with both credited as co-authors [39]. Other reviews involved adolescents in either co-producing a lay summary of the findings and key recommendations for researchers [36] or in reviewing the summary of the review, with their feedback leading to revisions in the discussion Sect. [37].

Sellars and team involved adolescents in developing a dissemination strategy that moved beyond traditional academic articles. This approach ensured that the review's findings reached a wider audience through methods tailored to adolescent engagement [1]. In terms of knowledge mobilisation, Sanchez and colleagues formed a youth advisory board to lead the process of sharing the review's findings, though specific details on their contributions were not provided [38].

Challenges and facilitators to adolescent involvement in reviews

None of the included reviews reported any specific facilitators that supported adolescent involvement in the evidence synthesis process. Only one review, conducted by Sellars et al., reported financial constraints and limited time as barriers to adolescent involvement. These constraints impacted how and when adolescents could participate in the review, suggesting that resources can play a significant role in determining the extent of adolescent engagement [1].

In our umbrella review, most of the adolescent co-researchers lacked previous experience in systematic reviews or academic research. This meant that additional time was needed for training and for their full participation in technical stages, such as screening and data extraction. Another key challenge faced during the review process was the need for flexibility in accommodating the diverse schedules and commitments of adolescent co-researchers. Many of the co-researchers were balancing other responsibilities, such as school and work, which created difficulties in coordinating group discussions and timely completion of tasks such as screening and data extraction.

Impacts of the involvement process on adolescents and reviews

None of the reviews reported any formal assessment of the impacts of the involvement process on adolescents or the review itself. In terms of the positive impacts of involvement on adolescents, they were credited as co-authors in five papers [38–42].

Discussion

This umbrella review is the first to consolidate evidence on adolescent involvement in evidence syntheses on their engagement in health research. We identified 10 papers describing adolescent involvement in different types of reviews and provided examples of how adolescents were involved at different stages of the current review. Our findings indicate that adolescents were involved in nearly all stages of the review process, demonstrating that adolescents can be successfully engaged throughout evidence synthesis. A diverse range of creative and participatory methods, such as informal consultations, youth advisory groups, hackathons, and collaborative meetings, were used to involve adolescents at different stages.

Current landscape and recommendations for adolescent involvement in evidence syntheses

While adolescents were engaged at almost all stages of the review process, they were most frequently involved in the interpretation and write-up stages. This is congruent with existing research, which shows that adolescents are more commonly involved in later stages of health research projects [4, 43]. However, this contrasts with findings from other reviews on overall stakeholder

involvement in realist reviews [18, 44], who reported that stakeholders were frequently engaged across clarifying the scope, developing programme theories in realist reviews, and participating in data analysis and synthesis. The higher engagement of adolescents in the interpretation and write-up stages of reviews may be because these stages require less specialised technical expertise, making them more accessible for adolescent involvement. The nature of adolescent involvement in most reviews was consultative, where their input and advice were sought, with only two reviews actively engaging adolescents as co-researchers. This trend mirrors findings from Power and colleagues, who noted that most realist reviews involved stakeholders as consultants and advisors at specific stages [44]. This may be attributed to practical constraints, such as the technical complexity of some stages of the review process (e.g. conducting searches) or resource limitations, which may make it unfeasible to involve adolescents at a higher level [1]. A wide variety of methods used to engage adolescent's contrasts with the more conventional methods used for overall stakeholder involvement in evidence syntheses. For stakeholders, commonly used methods included focus-group discussions, interviews, ranking techniques, and meetings or workshops with advisory groups. The difference suggests that more innovative and diverse approaches are necessary to effectively engage adolescents in the review process compared to general stakeholders. This corroborates with broader research on adolescent involvement in health research, which emphasises the importance of using more engaging and flexible methods to sustain meaningful adolescent involvement [45].

Given the wide variation in the number of adolescents engaged at different stages of the review process, there is no set number of adolescents required for involvement in evidence syntheses; rather, the number depends on their role and level of involvement in the project. In our umbrella review, we engaged five co-researchers at different stages of the review process, tailoring their involvement to their interests and the tasks available. The same outcomes could potentially have been achieved with just one or two adolescents, but five were involved to accommodate their limited availability due to other commitments. Involving multiple adolescents is also considered good practice because it makes the process more adolescent-friendly and accessible. At the interpretation stage, in particular, it is important to ensure diversity in the group of adolescents. This need for diverse input likely explains why a higher number of adolescents were engaged as advisors during this phase in both the included reviews and our umbrella review.

The findings indicate that both adolescents with and without previous professional or lived experience can be successfully involved in conducting evidence syntheses, depending on their role in the project. For example, reviews that engaged adolescents with prior experience, either through contributing to research or through lived experience related to the topic, tended to involve them in tasks such as planning the review or interpreting the findings based on their experiences [1, 36, 40, 41]. In contrast, reviews that involved adolescents without prior experience often engaged them as co-researchers in conducting various stages of the evidence synthesis itself [39, 42]. This pattern aligns with adolescent involvement in our review, where students without previous experience were engaged as co-researchers across multiple stages of the umbrella review. Meanwhile, advisors with previous experience contributing to health research were involved specifically at the interpretation stage.

Process outcomes of adolescent involvement in evidence syntheses

Most of the reviews did not report any challenges, facilitators, or overall recommendations or best practices for involving adolescents in evidence syntheses. The few challenges that were mentioned aligned with the challenges reported in other case studies of adolescent involvement in reviews [46] or general barriers found in broader adolescent involvement literature, such as resource limitations, time constraints, and logistical issues [35, 46]. One of the few recommendations highlighted in the reviews concerned not requiring ethics approval for adolescent involvement, which has been a point of ambiguity in previous reviews on stakeholder involvement in evidence syntheses [18, 21]. Similarly, reviews did not report on any positive or negative impacts of involvement in the review for the adolescents. However, adolescents were acknowledged as co-authors in five reviews [38–42], which can further strengthen adolescents' CVs and may have implications for their academic and career outcomes [15]. The insufficient evidence on the impacts of adolescent involvement in the included reviews due to a lack of formal and rigorous evaluation highlights a key missed opportunity to identify the processes through which adolescent involvement can strengthen the evidence syntheses.

Evaluation and reporting of adolescent involvement

Other key details missing from the papers included a description of the training provided to adolescents, and any ethical implications considered during their involvement. This lack of reporting on crucial elements of the adolescent involvement process can be attributed to the absence of formal, planned evaluations of adolescent participation in evidence syntheses [47], and a lack of reporting tools or guidelines to report the findings. The issue of

inadequate evaluation and poor reporting of adolescent involvement aligns with similar findings in reviews of overall stakeholder involvement in evidence syntheses [21, 44]. Pollock and colleagues found that the majority of the reviews in their study did not conduct formal evaluations and did not use any reporting tools to present how stakeholders were engaged. Power and colleagues highlighted similar issues with poor reporting and a lack of detail in reviews on how stakeholders were involved [44]. To address this, researchers need to use evaluation frameworks to formally evaluate the adolescent involvement process in evidence syntheses [38]. Furthermore, there is a need to adhere to reporting guidelines like the Guidance for Reporting Involvement of Patients and the Public (GRIPP) checklist [48] or ACTIVE framework [22] to ensure transparency and consistency in reporting of adolescent involvement in evidence syntheses.

Limitations

This umbrella review has some limitations. First, it was restricted to English-language reviews. Second, relevant reviews using different terminology for adolescent involvement may have been missed despite a broad search strategy. Third, it focused solely on adolescents aged 10–24, limiting generalisability to younger children. Fourth, the original search for this review was conducted in December 2021. While we made an effort to update it by screening articles included in a more recently published umbrella review and by hand-searching two relevant journals for papers published in the last 2 years, it is still possible that some relevant papers were not included. Lastly, the study screening and selection were primarily conducted by a single reviewer, which may have increased the risk of bias in the study selection process.

Conclusion

In this umbrella review, we found that adolescents can contribute to various stages of evidence synthesis, particularly in interpretation and dissemination of findings, using a wide range of methods. The predominantly consultative nature of adolescent involvement, often limited to later stages in most of the included reviews, reflects practical constraints and a reliance on tasks that require less specialised expertise. The identification of mechanisms through which adolescent involvement impacts review outcomes is significantly limited by inadequate reporting and evaluation. Addressing these gaps through the adoption of established reporting guidelines and systematic evaluations will be crucial for improving both the quality of adolescent involvement and the evidence synthesis process itself.

Abbreviations

UNCRC UN Convention on the Rights of the Child
PPI Public and patient involvement
YAGs Youth advisory groups

Supplementary Information

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Supplementary Material 1. Supplementary Table 1. Characteristics of Included Reviews. Supplementary Table 2. Methods, Stages, and Levels of Adolescent Involvement in Reviews. Supplementary Table 3. Process and Outcomes of Adolescent Involvement in Reviews.

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Authors' contributions

AW and KH conceptualised and wrote the paper with valuable inputs from MS, CW, ML, DB, and JH, QK. MS, DB, ML, and QK, contributed to the screening, data extraction, and analysis of this review, while CW and JH led the participatory workshops with the youth advisory group as young co-researchers. All authors have reviewed and approved the final manuscript.

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Data availability

All data files and supplementary materials for this review can be accessed at https://osf.io/cx7y9/?view_only=4f40ba5530f64c608c405ce66a4a7243.

Declarations

Ethics approval and consent to participate

Only secondary data was included in this umbrella review; therefore, ethical approval or informed consent of participants was not required.

Competing interests

The authors declare that they have no competing interests.

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