BMJ Open

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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-069695
Article Type:	Protocol
Date Submitted by the Author:	29-Oct-2022
Complete List of Authors:	Warraitch, Azza; Trinity College Dublin, Trinity Centre for Global Health; Trinity College Dublin, School of Psychology Bruce, Delali; Trinity College Dublin, Trinity Centre for Global Health; Stanford University, School of Engineering Lee, Maria; Trinity College Dublin, Trinity Centre for Global Health; Trinity College Dublin, School of Psychology Curran, Paul; Trinity College Dublin, School of Psychology Khraisha, Qusai; Trinity College Dublin, Trinity Centre for Global Health; Trinity College Dublin, School of Psychology Hadfield, Kristin; Trinity College Dublin, Trinity Centre for Global Health; Trinity College Dublin, School of Psychology
Keywords:	PAEDIATRICS, Protocols & guidelines < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Community child health < PAEDIATRICS

Involving adolescents in the design, implementation, evaluation, and dissemination of health research: an umbrella review protocol

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Abstract

Introduction: A lack of awareness on *how* to engage adolescents in research has been reported as one of the barriers to meaningful youth involvement in health research. Currently available guidelines on youth involvement are limited in terms of the scope (e.g., focused on limited health research areas), content (e.g., include broad principles), and context (e.g., most guidelines are from high-income countries) for which the guidelines are applicable. To address this, we will develop a set of comprehensive guidelines based on consolidated evidence on youth involvement in health research. To inform these guidelines, we are first conducting an umbrella review to i) summarize and synthesize findings from reviews on involving adolescents in health research, ii) consolidate the challenges experienced in youth involvement and the recommendations to mitigate these challenges, iii) identify best practices, and iv) identify gaps and methodological weaknesses in the extant literature on involving adolescents in health research.

Methods and analysis: We will include review articles exploring adolescents' involvement in studies aiming to improve their physical or mental health. Databases to be searched include Cochrane Database of Systematic Reviews, Medical Literature Analysis and Retrieval System Online (MEDLINE), Scopus, Embase, PsycINFO, PsycArticles, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Epistemonikos, and Health Systems Evidence. A grey literature search will be conducted in Web of Science, ProQuest, Google Scholar, and PROSPERO, supplemented by a hand search of the reference lists of eligible reviews, relevant journals, websites of related organizations, and input from experts. Data will be analyzed using narrative synthesis.

Ethics and dissemination: Ethical approval is not required as we are not collecting participant data as part of this review. The findings of this umbrella review will be disseminated through peer-reviewed publications, participatory workshops, and academic conferences.

Umbrella review registration: PROSPERO CRD42021287467.

Strengths and limitations of this study

- This umbrella review consolidates evidence from a highly varied range of reviews on youth involvement in health research, using a rigorous methodology and a comprehensive search strategy.
- This umbrella review will be conducted with active involvement from adolescents throughout to improve the relevance, quality, and dissemination of the findings.
- Only reviews published in English will be included.

Keywords: Youth involvement, Participatory action research, Public and Patient Involvement (PPI), Health Research, Adolescent health.

Introduction

Adolescents aged 10–24 years comprise 24% of the world's population (1). In the past two decades, there has been a global shift in attention towards the promotion of adolescent health (2, 3). The recent prioritization of adolescent health in global strategies (4, 5) is underpinned by a number of factors. First, adolescents experience a considerable proportion of the global population's disease burden, attributed to different communicable and non-communicable diseases and injuries (6, 7). Around 168 million Disability-Adjusted Life Years (DALYs) are lost to adolescents' mental health and physical health difficulties (6, 7). Second, establishing healthy behavioral patterns and minimizing exposure to risk factors among adolescents is a strong determinant for future health trajectories and can also improve the health of the next generation (3, 6). Third, the substantial improvements in maternal and child health outcomes, which have been achieved in recent decades through considerable global efforts, are at risk without adequate investments in adolescent health (3, 6, 8, 9). Lastly, improvement in adolescent health outcomes promotes their productivity, academic success, and future financial stability, and reduces the direct and indirect costs associated with disease burden, resulting in societal and economic benefits (3, 6, 10-13). For these reasons, adolescence is now widely considered a critical period in which to invest (3, 5, 9, 14), as reflected in the increase in development assistance for adolescent health, from 109.7 million dollars in 2003 to 528.5 million dollars in 2015 (15).

Heralded by the UN Convention on the Rights of the Child, the involvement of young people in all decisions that affect their lives, including those relating to health and wellbeing, is now widely acknowledged as their fundamental right (16, 17). One method of including youth in such decisions is to engage them in the research process. Health research is an important avenue for informing the design of healthcare services and care provision to young people, as well as health

policy. Meaningful involvement of youth in health research is defined as "research that is done 'with' or 'by'" young people, "not 'to', 'about' or 'for' them" (18, 19). Adolescents can be engaged to define and prioritize research questions, design the research process, ensure the appropriateness of the research methodology for the young population, collect and analyze data, and disseminate the research findings (17, 19-24). There are several frameworks to describe the involvement of children and adolescents in research and health services. These include Hart's ladder of young people's participation framework(25), Shier's pathways to participation framework (26), Treseder's non-linear model of participation (27), Wong's TYPE Pyramid framework (28), Arunkumar's rope ladder model (29), and the five-dimensional framework for young people's involvement in health research (19). The frameworks most commonly used to describe and evaluate youth involvement are those proposed by Roger Hart(25) and Harry Shier (26).

In recent years, there has been an increasing emphasis on the meaningful involvement of adolescents in health research, using participatory approaches (17, 23, 30-35). Three driving factors explain the context of this change around the involvement of adolescents in health research and service delivery(33). The first one is "consumer movement" (36), also equated with the term "user involvement", emerging in the 1970s, that focuses on the integration of patients' views to ensure responsive and acceptable health services (33, 37). This approach has assumed a central position in NHS health policy for adults since the late nineties (38-40) and now encompasses the involvement of adolescents in the design and delivery of health services and research (22, 33, 41).

Second, Article 12 of the UN Convention on the Rights of the Child (16) emphasized that children and adolescents have a right to contribute to decisions regarding all matters relevant to young people and that their views must be taken into account. Almost all countries have now ratified this convention to achieve health equity by sharing power over decisions about adolescents (6, 42).

This has led to a change in the perception of adolescents as social actors rather than passive recipients of care and services designed and delivered by adult professionals (33, 34). This has also resulted in an unprecedented demand for the representation of adolescents in health-related decision-making, with multiple health and funding organizations strongly advocating for the meaningful involvement of adolescents in health research to achieve the 2030 agenda for Sustainable Development (3, 17, 19, 43-45).

Third, preliminary evidence on the impact of adolescents' contribution in health research highlights multiple benefits of youth involvement from an operational, developmental, and societal perspective (3, 6, 17, 19, 22, 33, 46, 47), further strengthening the cause for youth involvement. From an operational perspective, the involvement of adolescents improves research in several ways: i) it ensures that the research questions reflect the needs and preferences of adolescents (17, 19, 21, 48), ii) enhances the recruitment and retention rates of participants (19, 49-53), iii) improves data collection (19, 21, 54-58), iv) improves data analysis by bringing unique insight of adolescents in translating the responses (19, 59, 60), and v) facilitates broader and more effective dissemination of the findings (6, 19, 56, 61). Moreover, organizations that work with adolescents report an overall change in the organization's culture to be more inclusive (62). From a developmental perspective, several positive outcomes have been reported for adolescents who contribute to research projects, including i) learning new research skills (19, 46, 63-68), ii) increased knowledge about health topics (19, 46, 50, 69-71), iii) better health outcomes (19, 46, 70, 72), and iv) better academic or career outcomes (6, 19, 22, 63, 73-75). At the societal level, the involvement of adolescents has been linked with an increased awareness of different health issues in the community (17, 19, 62, 76-79).

Despite growing recognition of the fundamental rights of adolescents to contribute to research and

the potential benefits of involving them in research, Sellars et al. (2020) (17) found that less than 1% of studies on child and adolescent health report involving adolescents as part of advisory groups. While involving young people in health research is on the rise, the overall number of studies that involve youth is still low (19). This under-involvement of adolescents in health research may be attributed to the challenges or barriers experienced by researchers and adolescents contributing to research projects (17). These challenges include a lack of awareness of the evidence on youth involvement (19, 80), a need for extensive training to effectively engage youth in research (17, 19, 47, 56, 80-86), limited training resources and a lack of a comprehensive set of guidelines on engaging youth in health research (19, 47, 80, 87, 88), inadequate funding to support meaningful youth involvement (82, 85, 89), difficulties in recruiting and retaining adolescents (85, 86, 90), complex ethical procedures such as additional consent and assent requirements, and compliance with different safeguarding practices that vary for different contexts (48, 56, 91). To address some of the highlighted challenges to meaningful youth involvement, we aim to develop a comprehensive set of guidelines for involving youth in health research. This umbrella review will inform the development of these guidelines by consolidating the review-level evidence on youth involvement in health research. There are numerous reviews on youth involvement in health research. However, these reviews focus on specific areas of health research (e.g., sexual and reproductive health, mental health), certain types of youth involvement approaches (e.g., peer-mediated interventions, participatory action research), specific locations (e.g., United States of America, India), and are heterogenous in their methods (e.g., search different databases, use different age groups etc.) and findings. Furthermore, there is little overlap in the studies that are included in these reviews, highlighting the need to bring together all available evidence on youth involvement in different areas of health research in different contexts and to translate these findings

into recommendations. Given the broad scope of the research objectives and the heterogeneity in the extant literature, an umbrella review is a more suitable choice of review than a systematic review of primary studies (92).

Therefore, we aim to conduct an umbrella review to i) summarize and synthesize findings from reviews on involving adolescents in health research, ii) consolidate the challenges experienced in youth involvement and the recommendations to mitigate these challenges, iii) identify the best practices or recommendations on involving adolescents in health research, and iv) identify gaps and methodological weaknesses in the extant literature.

Methods and analysis

This umbrella review will be conducted as per the Cochrane guidelines for overviews of reviews (93). However, some elements—types of reviews to be included and the appraisal method, in particular—have been adapted (described below) to suit the objectives of the umbrella review. We followed the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) guidelines in reporting this protocol (Additional file 1). We will report findings in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) statement (94) given that the PRISMA extension for overviews of reviews (Preferred Reporting Items for Overviews of Reviews; PRIOR) is under development and is thus not available for this umbrella review (95). The umbrella review has been registered with the International Prospective Register of Systematic Reviews (PROSPERO CRD42021287467). The PROSPERO registration was updated to pre-register some changes to the methodology described below.

Search strategy

The search strategy for this umbrella review includes keywords for; a) population (adolescents aged 10-24 years) (96), b) intervention or exposure (involvement of adolescents in health

research), c) condition under study (health of adolescents), and d) review type (including narrative reviews, targeted reviews, rapid reviews, scoping reviews, literature reviews, qualitative reviews, integrated reviews, evidence maps, critical reviews, mixed methods reviews, overviews, state of the art reviews, practitioner reviews, systematic reviews, as well as meta-analyses) using Boolean syntax. Authors AW and KH developed the search strategy in consultation with a research librarian (GF) at Trinity College Dublin.

A commonly reported problem in studying youth involvement is the inconsistent use of terminologies and a wide range of methodologies classified as youth involvement (19, 47). The search strategy is attached in the supplementary materials (Additional File 2).

Information sources

Electronic databases

We will search Cochrane Database of Systematic Reviews, Medical Literature Analysis and Retrieval System Online (MEDLINE), Scopus, Embase, PsycINFO, PsycArticles, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Epistemonikos, and Health Systems Evidence databases for potentially eligible reviews conducted up to 30th November 2021.

Grey literature search

The grey literature search involves several components. First, a simplified search strategy – based on different combinations of fewer key search terms – will be used to search Google Scholar for additional reviews. The Google Scholar search will be restricted to the first 10 pages. Second, we will identify the top 10 ranking pediatrics, perinatology, and child health journals using the Scimago Journal and Country Rank list for 2020 (17). A similar simplified version of the search strategy will be used to search these journals for additional reviews that could be potentially

eligible for inclusion. Third, Web of Science and ProQuest will be searched to identify additional conference abstracts, theses, reports, and unpublished relevant reviews. The search strategy will be modified to suit the interface of these databases, as required. The search strategy for Web of Science is attached in the supplementary materials (Additional File 3). Fourth, we will search for relevant reviews registered on PROSPERO. Authors of potentially eligible reviews will be contacted to check whether the reviews are close to completion or have been completed. The authors will be requested to share the extracted data for inclusion in the umbrella review for complete or close to completion reviews. The number of contacts made and the number of authors who agreed to share the data will be recorded and reported. Fifth, websites of relevant organizations will also be searched for grey literature. This will involve compiling a list of organizations (including governmental, non-profit, and funding organizations) working on adolescents' health. We will conduct a targeted search of up to 20 pages of Google, the Mental Health Innovation Network database, and including organizations known to the authors. Then, we will search for relevant documents by running a simplified search strategy, like the one used for searching Google Scholar, on the website homepages of these organizations. The first ten pages of the results will be searched. Websites without a search option will be hand-searched. We will also search Google for youth health organizations in low- and middle-income countries and search the website of one organization (top google result) for each country. Names of all organizational websites searched, and the titles and URL links to eligible materials will be extracted in the excel spreadsheet for grey literature, which will be posted on the review's Open Science Framework (OSF) page. Sixth, we will contact five to ten experts in youth involvement in health research. They will be regarded as an expert if, a) they oversee youth involvement in health research component at a funding organization (e.g., Wellcome Trust, Grand Challenges

Canada) or youth health organization and/or, b) have conducted studies which involved adolescents as collaborators at different stages of the research process. We will include experts from high-, middle-, and low-income countries. After identifying potential experts to be contacted, we will send them an email stating the aims of the umbrella review, eligibility criteria for reviews, and a statement requesting that they share the references of any relevant materials they might be familiar with. Seventh, reference lists of all eligible reviews will be reviewed to identify further relevant reviews. Finally, all the eligible reviews will be entered in the connectedpapers software to identify similar papers. This comprehensive strategy aims to identify all published and unpublished reviews on this topic and get the broadest range of views possible for inclusion in the umbrella review.

Data management

All references from electronic databases will be exported to Covidence. We will record the search date, the number of results for each database and each combination of the search terms for grey literature search. For the grey literature, titles and URL links to potentially relevant documents will be entered in an excel spreadsheet for grey literature (97).

Eligibility Criteria

Study Design

Only review articles will be eligible for inclusion in this umbrella review. Although the Cochrane Overview of reviews guidelines recommend including systematic reviews and meta-analysis, we will include review articles of all types, including 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, as well as meta-analyses (98). This adaptation to the

guidelines is due to the qualitative nature of the outcomes of interest and to ensure the inclusion of a wide range of literature on youth involvement. This adaptation to the guidelines is common in umbrella reviews focusing on qualitative data and outcomes(99).

Participants

We will only include reviews that discuss youth-specific results; the age range of participants in studies included in the review can vary, but the target population of the review must include adolescents. Adolescents are young people between the ages of 10 to 24 years as defined by Sawyer et al. (96). All reviews focusing on children and adolescents irrespective of the age range (as long as these include some studies for adolescents aged between 10 and 24 years) will be included, but primary studies where the age range of the target population is below ten years or above 24 years will be excluded. Reviews and studies where the age range is not mentioned, rather the terms children and adolescents are listed will be included. No other restrictions will be applied based on demographic characteristics or context.

Intervention

Reviews exploring youth involvement in studies that focus on the promotion of physical and mental health or treatment of physical and mental health difficulties among adolescents will be eligible. Youth involvement refers to a wide range of methods and strategies used to involve young people in the design, conduct, analysis and dissemination of research on adolescent health.

Outcomes

Reviews including one or more of the following outcomes will be eligible for inclusion: i) strategies that have been used to involve adolescents in conducting health research, ii) recommendations for involving adolescents in health research (best practices), iii) barriers to

meaningful youth involvement, iv) mitigation strategies to address these barriers and, v) evidence gaps in youth involvement in health research.

Other criteria

Only reviews published in the English language will be considered for inclusion. Reviews where data extraction tables for the primary studies (applicable to systematic, rapid, and scoping reviews) are inaccessible will be excluded. As per the Cochrane guidelines for overviews of reviews (93), if a review's research objectives and scope are broader than the current umbrella review, the subset of primary studies meeting the review's eligibility criteria will be included in this umbrella review.

Selection of studies

Search results will be imported into Covidence for the removal of duplicate references. The eligibility criteria will be discussed among researchers conducting the title and abstract screening to ensure mutual understanding of the criteria. Title and abstract screening of the studies will be undertaken by two postgraduate-level psychology students and an adolescent co-researcher. They will first conduct a pilot screening of 1% of randomly selected search results. Any discrepancies will be discussed and resolved before proceeding with title and abstract screening for the rest of the articles. AW will conduct the title and abstract screening of all articles, while co-researchers (QK) and an adolescent researcher will conduct title and abstract screening of 25% of articles to minimize the risk of bias. Where eligibility cannot be determined based on abstract, such articles will be labeled ambiguous and reviewed in full.

AW will conduct full-text screening and extract data from all eligible articles, while QK and an adolescent researcher will conduct full-text screening and data extraction for 10% of articles. Reasons for exclusion will be recorded for all excluded articles at this stage. Any discrepancies

or disagreements will be resolved through discussion among these three researchers and, if required, through discussion with a fourth researcher (KH).

Overlap in primary studies across multiple reviews can give undue weightage to studies included more than once in the synthesis of findings. It is recommended to address the risk of overlap at the inclusion, data extraction, or synthesis stage (100). We will assess the overlap in primary studies at the data extraction and synthesis stage by creating a citation matrix (93, 101) where the primary studies will be cross-linked with the reviews they are included in. The reviews will be listed in columns, and the primary studies will be added in rows, with a tick mark added under all reviews that include a primary study. The overlap will be quantified by calculating the corrected covered area measure (101) that indicates the degree of overlap. The citation matrix will help us ensure that the results of primary studies included in multiple reviews are only included once (100, 101). This citation matrix will be posted on the review's OSF page.

Data extraction

Data from the included reviews will be extracted using a data extraction form designed in Covidence. The data extraction form will be piloted by researchers extracting the data, using 1% of eligible full-text articles. Inter-rater reliability between the researchers will be assessed using the kappa statistic. Data on results will be extracted only from the included reviews. Data will be extracted on:

a) Characteristics of eligible reviews including review title, names and contact details of study authors, publication type (e.g., article, conference abstract, report, etc.), review type (scoping, narrative, systematic, etc.), the age range of study population in the review, the condition under study (e.g., physical health, mental health, or specific disease/disorder),

aim of the review, definition of youth involvement used, search strategy, databases and grey literature sources searched, search end date, method of synthesis, and tool used to appraise the risk of bias for the primary studies.

b) Characteristics of primary studies include their eligibility criteria, the number of primary studies included in the review, the study design of primary studies, and the risk of bias results for the primary studies.

c) Findings will consist of the use of different youth involvement strategies, level of youth involvement, challenges, or barriers in the use of youth involvement strategies, recommendations to address these barriers, best practices in youth involvement in health research, limitations of the review, and gaps identified in the literature.

Risk of bias assessment

A MeaSurement Tool to Assess systematic Reviews-2 (AMSTAR 2) (102) will be used to assess the methodological quality of included systematic reviews. The risk of bias assessments conducted for the primary studies in the included reviews will be narratively summarized. AW will conduct the risk of bias assessment of all eligible systematic reviews, while a second reviewer will conduct the risk of bias assessment for 10% of eligible systematic reviews. Any discrepancies or disagreements will be resolved through discussion among these two researchers and, if required, through discussion with a third researcher (KH).

Narrative synthesis

A narrative synthesis will be conducted to analyze the data. The first step will include familiarization with the extracted data through close reading, followed by coding the extracted data using deductive coding. Then, the codes will be structured under broader themes. Finally,

these themes will be summarized in a descriptive and tabular form, centered around the research questions.

Patient and Public Involvement

Adolescents will be involved in the title and abstract screening, full-text screening, data extraction, analysis, and dissemination phases of this umbrella review. These adolescents will be invited to participate through local non-profit organizations and/or academic institutions. Specifically, an adolescent co-researcher will be recruited to conduct title and abstract screening for 25% of the articles and undertake full-text screening and data extraction for 10% of articles to ensure the representation of youth in the decision-making process. Another youth co-researcher will contribute to the data analysis by developing themes and writing up the narrative synthesis with AW. To increase the relevance of the findings, 6-8 members of a youth advisory group will be invited to share their interpretation of the results and reflections on the challenges and recommendations highlighted in the literature. Additionally, they will contribute by reviewing the outputs of this umbrella review and ensuring the language used is accessible and inclusive. We will also facilitate the young co-researchers and advisors to present the findings to the scientific community via video abstracts and to youth and lay audiences through dissemination methods determined by the youth themselves to ensure more effective and wider dissemination of the results.

Discussion

This review will bring together evidence on the most effective ways of involving adolescents in health research, challenges experienced in this process, and mitigation strategies which have been recommended to address or prevent these challenges. These findings will inform the development of guidelines on involving adolescents in health research. The need for a comprehensive set of

guidelines and resources on involving adolescents in health research has been highlighted by youth researchers (80) and studies (82, 103-106). These guidelines will facilitate researchers to collaborate with adolescents more effectively, leading to more meaningful involvement of adolescents in research.

This umbrella review has a few limitations. The search for eligible reviews will be restricted to the English language. Additionally, while the search strategy incorporates a wide range of terms to account for the variation in terminology around youth involvement, there is a possibility that relevant reviews indexed using different terms will not be included. Moreover, umbrella reviews are based on the information presented in the review articles and are therefore limited by the quality of extracted data in the included reviews. Finally, there is a possibility of missing relevant data on youth involvement in health research that has not previously been included in reviews. Any deviations to the submitted protocol will be documented as amendments to the PROSPERO registration.

Ethics and dissemination: Only reviews will be included in this umbrella review; therefore, ethical approval is not required. The findings of this umbrella review will be disseminated through peer-reviewed publications, participatory workshops, and academic conferences.

Supplementary Information

Additional file 1. PRISMA-P Checklist.

Additional file 2. Search strategy for MEDLINE

Additional file 3. Search strategy for Web of Science

Competing interests

The authors declare that they have no competing interests.

Funding statement

Azza Warraitch received the Ussher Fellowship from Trinity College Dublin to support her PhD research, including this umbrella review. She received a Trinity Research in Social Sciences (TRiSS) Research Fellowship to conduct participatory workshops with youth as part of this umbrella review. The funders did not play any role in design of this review.

Authors' contributions

AW and KH conceptualized and wrote the protocol with valuable inputs from QK. DB, ML, PC will contribute to the screening, data extraction and analysis of this review as young co-researchers. All authors have reviewed and approved the final manuscript.

Acknowledgments

We would like to acknowledge all members of the Trinity Centre for Global Health and School of Psychology – especially Drs. Sadhbh Byrne, Frédérique Vallieres and Elizabeth Nixon – for their valuable inputs. We would also like to thank Ms. Geraldine Fitzgerald, the research librarian at the School of Medicine, Trinity College Dublin, for her feedback and input on the search strategy for this umbrella review.

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PRISMA-P 2015 Checklist

This checklist has been adapted for use with systematic review protocol submissions to BioMed Central journals from Table 3 in Moher D et al: Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* 2015 **4**:1

An Editorial from the Editors-in-Chief of *Systematic Reviews* details why this checklist was adapted - **Moher D, Stewart L & Shekelle P:** Implementing PRISMA-P: recommendations for prospective authors. *Systematic Reviews* 2016 **5**:15

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
ADMINISTRATIVE INFORMATION					
Title					
Identification	1a	Identify the report as a protocol of a systematic review	☒	☐	1-2
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	☐	☒	
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract	☒	☐	37
Authors					
Contact	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	☒	☐	6-12
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	☒	☐	368-371
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	☐	☒	
Support					
Sources	5a	Indicate sources of financial or other support for the review	☒	☐	363-367 372-377
Sponsor	5b	Provide name for the review funder and/or sponsor	☒	☐	363-367
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	☒	☐	367
INTRODUCTION					

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
Rationale	6	Describe the rationale for the review in the context of what is already known	☒	☐	48-142
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	☒	☐	143-147
METHODS					
Eligibility criteria	8	Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review	☒	☐	223-260
Information sources	9	Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage	☒	☐	172-217
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	☒	☐	160-171 Additional file 2
STUDY RECORDS					
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	☒	☐	218-222
Selection process	11b	State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis)	☒	☐	261-286
Data collection process	11c	Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	☒	☐	287-306
Data items	12	List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications	☒	☐	287-306
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	☒	☐	287-306
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	☒	☐	307-314
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	☐	☒	
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., I^2, Kendall's tau)	☐	☒	
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)	☐	☒	

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	☒	☐	315-320
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)	☐	☒	
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)	☐	☒	

Search strategy for MEDLINE

#	Query	Limiters/Expanders
S17	S3 AND S8 AND S15 AND S16	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S16	AB review OR TI review	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S15	S13 OR S14	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S14	S9 OR S10 OR S11 OR S12	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S13	Involv* OR "advisory group*" OR "research advisory group" OR "research advisory panel*" OR "advisory panel" OR "advisory committee*" OR "advisory board*" OR "youth engagement" OR "patient and public involvement" OR "public and patient involvement" OR "public patient involvement" OR "community based participatory research" OR "youth particip*" OR "adolescent engagement" OR "participatory design" OR "participatory action" OR "needs assessment*" OR "co produc*" OR "co design" OR "Human centered design" OR "Human centred design" OR "User centered design" OR "User centred design" OR "user involvement" OR "peer researcher*" OR "co researcher*" OR "Patient Participation" OR "young researcher*" OR "lived experience"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S12	(MM "Community Participation+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S11	(MM "Community-Based Participatory Research+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S10	(MM "Patient Participation")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S9	(MM "Stakeholder Participation+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S8	S4 OR S7	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S7	S5 OR S6	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S6	(MM "Young Adult")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S5	(MM "Adolescent")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

S4	AB (child* OR youth OR adolescen* OR "young people" OR "Young person*" OR "Young adult*" OR teen* OR juven*) OR TI (child* OR youth OR adolescen* OR "young people" OR "Young person*" OR "Young adult*" OR teen* OR juven*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S3	S1 OR S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S2	AB "health research" OR TI "health research"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S1	(MM "Health Services Research+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

Search strategy for Web of science

(((TS=(review)) AND TS=("Health research")) AND TS=(child* OR youth OR adolescen* OR "young people" OR "Young person*" OR "Young adult*" OR teen* OR juven*)) AND TS=(Involv* OR "advisory group*" OR "research advisory group" OR "research advisory panel*" OR "advisory panel" OR "advisory committee*" OR "advisory board*" OR "youth engagement" OR "patient and public involvement" OR "public and patient involvement" OR "public patient involvement" OR "community based participatory research" OR "youth particip*" OR "adolescent engagement" OR "participatory design" OR "participatory action" OR "needs assessment*" OR "co produc*" OR "co design" OR "Human centered design" OR "Human centred design" OR "User centered design" OR "User centred design" OR "user involvement" OR "peer researcher*" OR "co researcher*" OR "Patient Participation" OR "young researcher*" OR "lived experience")

BMJ Open

Involving adolescents in the design, implementation, evaluation, and dissemination of health research: an umbrella review protocol

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-069695.R1
Article Type:	Protocol
Date Submitted by the Author:	27-Mar-2023
Complete List of Authors:	Warraitch, Azza; Trinity College Dublin, Trinity Centre for Global Health; Trinity College Dublin, School of Psychology Bruce, Delali; Trinity College Dublin, Trinity Centre for Global Health; Stanford University, School of Engineering Lee, Maria; Trinity College Dublin, Trinity Centre for Global Health; Trinity College Dublin, School of Psychology Curran, Paul; Trinity College Dublin, School of Psychology Khraisha, Qusai; Trinity College Dublin, Trinity Centre for Global Health; Trinity College Dublin, School of Psychology Hadfield, Kristin; Trinity College Dublin, Trinity Centre for Global Health; Trinity College Dublin, School of Psychology
Primary Subject Heading:	Global health
Secondary Subject Heading:	Health services research
Keywords:	PAEDIATRICS, Protocols & guidelines < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Community child health < PAEDIATRICS

Involving adolescents in the design, implementation, evaluation, and dissemination of health research: an umbrella review protocol

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Abstract

Introduction: A lack of awareness on *how* to engage adolescents in research has been reported as one of the barriers to meaningful youth involvement in health research. Currently available guidelines on youth involvement are limited in terms of the scope (e.g., focused on limited health research areas), content (e.g., include broad principles), and context (e.g., most guidelines are from high-income countries) for which the guidelines are applicable. To address this, we will develop a set of comprehensive guidelines based on consolidated evidence on youth involvement in health research. To inform these guidelines, we are first conducting an umbrella review to i) summarize and synthesize findings from reviews on involving adolescents in health research, ii) consolidate the challenges experienced in youth involvement and the recommendations to mitigate these challenges, iii) identify best practices, and iv) identify gaps and methodological weaknesses in the extant literature on involving adolescents in health research.

Methods and analysis: We will include review articles exploring adolescents' involvement in studies aiming to improve their physical or mental health. Databases to be searched include Cochrane Database of Systematic Reviews, Medical Literature Analysis and Retrieval System Online (MEDLINE), Scopus, Embase, PsycINFO, PsycArticles, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Epistemonikos, and Health Systems Evidence. A grey literature search will be conducted in Web of Science, ProQuest, Google Scholar, and PROSPERO, supplemented by a hand search of the reference lists of eligible reviews, relevant journals, websites of related organizations, and input from experts. Data will be analyzed using narrative synthesis.

Ethics and dissemination: Ethical approval is not required as we are not collecting participant data as part of this review. The findings of this umbrella review will be disseminated through peer-reviewed publications, participatory workshops, and academic conferences.

Umbrella review registration: PROSPERO CRD42021287467.

Strengths and limitations of this study

- This umbrella review consolidates evidence from a highly varied range of reviews on youth involvement in health research, using a rigorous methodology and a comprehensive search strategy.
- This umbrella review will be conducted with active involvement from adolescents throughout to improve the relevance, quality, and dissemination of the findings.
- Only reviews published in English will be included.

Keywords: Youth involvement, Participatory action research, Public and Patient Involvement (PPI), Health Research, Adolescent health.

Introduction

Adolescents aged 10–24 years comprise 24% of the world's population (1). In the past two decades, there has been a global shift in attention towards the promotion of adolescent health (2, 3). The recent prioritization of adolescent health in global strategies (4, 5) is underpinned by a number of factors. First, adolescents experience a considerable proportion of the global population's disease burden, attributed to different communicable and non-communicable diseases and injuries (6, 7). Around 168 million Disability-Adjusted Life Years (DALYs) are lost to adolescents' mental health and physical health difficulties (6, 7). Second, establishing healthy behavioral patterns and minimizing exposure to risk factors among adolescents is a strong determinant for future health trajectories and can also improve the health of the next generation (3, 6). Third, the substantial improvements in maternal and child health outcomes, which have been achieved in recent decades through considerable global efforts, are at risk without adequate investments in adolescent health (3, 6, 8, 9). Lastly, improvement in adolescent health outcomes promotes their productivity, academic success, and future financial stability, and reduces the direct and indirect costs associated with disease burden, resulting in societal and economic benefits (3, 6, 10-13). For these reasons, adolescence is now widely considered a critical period in which to invest (3, 5, 9, 14), as reflected in the increase in development assistance for adolescent health, from 109.7 million dollars in 2003 to 528.5 million dollars in 2015 (15).

Heralded by the UN Convention on the Rights of the Child, the involvement of young people in all decisions that affect their lives, including those relating to health and wellbeing, is now widely acknowledged as their fundamental right (16, 17). One method of including youth in such decisions is to engage them in the research process. Health research is an important avenue for informing the design of healthcare services and care provision to young people, as well as health

policy. Meaningful involvement of youth in health research is defined as "research that is done 'with' or 'by'" young people, "not 'to', 'about' or 'for' them" (18, 19). Adolescents can be engaged to define and prioritize research questions, design the research process, ensure the appropriateness of the research methodology for the young population, collect and analyze data, and disseminate the research findings (17, 19-24). There are several frameworks to describe the involvement of children and adolescents in research and health services. These include Hart's ladder of young people's participation framework (25), Shier's pathways to participation framework (26), Treseder's non-linear model of participation (27), Wong's TYPE Pyramid framework (28), Arunkumar's rope ladder model (29), and the five-dimensional framework for young people's involvement in health research (19). The frameworks most commonly used to describe and evaluate youth involvement are those proposed by Hart (25) and Shier (26).

Hart's ladder of young people's participation builds on Arnstein's ladder of citizen participation for adults (30). This framework refers to eight steps in the ladder of participation: manipulation, decoration, tokenism, assigned but informed, consulted and informed, adult-initiated shared decisions with children, child-initiated and directed, and child-initiated shared decisions with adults. Meaningful engagement begins at the fourth step of the ladder and ends with shared decision-making at the highest step (25). Shier proposed an alternative framework that focuses on elements of meaningful involvement. Shier's 'pathways to participation' model proposes five levels of involvement, where on the first level young people are listened to, on the second level they are supported to express their views, on the third level their views are taken into account, on the fourth level they are involved in decision-making processes and on the fifth level they share power and responsibility for decision making with the researchers (26). The relative simplicity of this model makes it one of the most widely used frameworks for youth involvement (19, 31).

In recent years, there has been an increasing emphasis on the meaningful involvement of adolescents in health research, using participatory approaches (17, 23, 31-36). Three driving factors explain the context of this change around the involvement of adolescents in health research and service delivery(31). The first one is "consumer movement" (37), also equated with the term "user involvement", emerging in the 1970s, that focuses on the integration of patients' views to ensure responsive and acceptable health services (31, 38). This approach has assumed a central position in the National Health Service (NHS) health policy for adults since the late nineties (39-41) and now encompasses the involvement of adolescents in the design and delivery of health services and research (22, 31, 42).

Second, Article 12 of the UN Convention on the Rights of the Child (16) emphasized that children and adolescents have a right to contribute to decisions regarding all matters relevant to young people and that their views must be taken into account. Almost all countries have now ratified this convention to achieve health equity by sharing power over decisions about adolescents (6, 43). This has led to a change in the perception of adolescents as social actors rather than passive recipients of care and services designed and delivered by adult professionals (31, 35). This has also resulted in an unprecedented demand for the representation of adolescents in health-related decision-making, with multiple health and funding organizations strongly advocating for the meaningful involvement of adolescents in health research to achieve the 2030 agenda for Sustainable Development (3, 17, 19, 44-46).

Third, preliminary evidence on the impact of adolescents' contribution in health research highlights multiple benefits of youth involvement from an operational, developmental, and societal perspective (3, 6, 17, 19, 22, 31, 47, 48), further strengthening the cause for youth involvement. From an operational perspective, the involvement of adolescents improves research in several

ways: i) it ensures that the research questions reflect the needs and preferences of adolescents (17, 19, 21, 49), ii) enhances the recruitment and retention rates of participants (19, 50-54), iii) improves data collection (19, 21, 55-59), iv) improves data analysis by bringing unique insight of adolescents in translating the responses (19, 60, 61), and v) facilitates broader and more effective dissemination of the findings (6, 19, 57, 62). Moreover, organizations that work with adolescents report an overall change in the organization's culture to be more inclusive (63). From a developmental perspective, several positive outcomes have been reported for adolescents who contribute to research projects, including i) learning new research skills (19, 47, 64-69), ii) increased knowledge about health topics (19, 47, 51, 70-72), iii) better health outcomes (19, 47, 71, 73), and iv) better academic or career outcomes (6, 19, 22, 64, 74-76). At the societal level, the involvement of adolescents has been linked with an increased awareness of different health issues in the community (17, 19, 63, 77-80).

Despite growing recognition of the fundamental rights of adolescents to contribute to research and the potential benefits of involving them in research, Sellars et al (17) found that less than 1% of studies on child and adolescent health report involving adolescents as part of advisory groups. While involving young people in health research is on the rise, the overall number of studies that involve youth is still low (19). This under-involvement of adolescents in health research may be attributed to the challenges or barriers experienced by researchers and adolescents contributing to research projects (17). These challenges include a lack of awareness of the evidence on youth involvement (19, 81), a need for extensive training to effectively engage youth in research (17, 19, 48, 57, 81-87), limited training resources and a lack of a comprehensive set of guidelines on engaging youth in health research (19, 48, 81, 88, 89), inadequate funding to support meaningful youth involvement (83, 86, 90), difficulties in recruiting and retaining adolescents (86, 87, 91),

complex ethical procedures such as additional consent and assent requirements, and compliance with different safeguarding practices that vary for different contexts (49, 57, 92). To address some of the highlighted challenges to meaningful youth involvement, we aim to develop a comprehensive set of guidelines for involving youth in health research. While there are several guidelines available on involvement of young people in health research, a recent review highlighted that these guidelines are limited in their scope, contexts, and the content that they cover (19). For example, overlooked areas of youth involvement such as involvement in the early and late stages of the research process, working with young people in LMICs, and working with those from disadvantaged groups, are some aspects that need to be emphasised in a set of comprehensive guidelines (81). While subject-specific guidelines, where they exist, may offer more targeted guidance on engaging young people in research on specific health issues, a comprehensive set of guidelines can be of use to a larger target audience of those working with youth in different types of health areas. Furthermore, as most of the principles of youth engagement are transdisciplinary (e.g., informed consent, power dynamics, inclusivity), an overall set of guidelines holds the potential to be useful and relevant to a wider audience working on a range of health research areas.

This umbrella review will inform the development of these guidelines by consolidating the review-level evidence on youth involvement in health research. This umbrella review will be followed by a rapid review to consolidate the recommendations from the existing guidelines on youth engagement in health research. Further details on the guideline development process can be accessed on the OSF page. There are numerous reviews on youth involvement in health research. However, these reviews focus on specific areas of health research (e.g., sexual and reproductive health, mental health), certain types of youth involvement approaches (e.g., peer-mediated interventions, participatory action research), specific locations (e.g., United States of America,

India), and are heterogenous in their methods (e.g., search different databases, use different age groups etc.) and findings. Furthermore, there is little overlap in the studies that are included in these reviews, highlighting the need to bring together all available evidence on youth involvement in different areas of health research in different contexts and to translate these findings into recommendations. Given the broad scope of the research objectives and the heterogeneity in the extant literature, an umbrella review is a more suitable choice of review than a systematic review of primary studies (93).

Therefore, we aim to conduct an umbrella review to i) summarize and synthesize findings from reviews on involving adolescents in health research, ii) consolidate the challenges experienced in youth involvement and the recommendations to mitigate these challenges, iii) identify the best practices or recommendations on involving adolescents in health research, and iv) identify gaps and methodological weaknesses in the extant literature.

Methods and analysis

This umbrella review will be conducted as per the Cochrane guidelines for overviews of reviews (94). However, some elements—types of reviews to be included and the appraisal method, in particular—have been adapted (described below) to suit the objectives of the umbrella review. We followed the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) guidelines in reporting this protocol (Additional file 1). We will report findings in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) statement (95) given that the PRISMA extension for overviews of reviews (Preferred Reporting Items for Overviews of Reviews; PRIOR) is under development and is thus not available for this umbrella review (96). The umbrella review has been registered with the International

Prospective Register of Systematic Reviews (PROSPERO CRD42021287467). The PROSPERO registration was updated to pre-register some changes to the methodology described below.

Search strategy

The search strategy for this umbrella review includes keywords for; a) population (adolescents aged 10-24 years) (97), b) intervention or exposure (involvement of adolescents in health research), c) condition under study (health of adolescents), and d) review type (including narrative reviews, targeted reviews, rapid reviews, scoping reviews, literature reviews, qualitative reviews, integrated reviews, evidence maps, critical reviews, mixed methods reviews, overviews, state of the art reviews, practitioner reviews, systematic reviews, as well as meta-analyses) using Boolean syntax. Authors AW and KH developed the search strategy in consultation with a research librarian (GF) at Trinity College Dublin.

A commonly reported problem in studying youth involvement is the inconsistent use of terminologies and a wide range of methodologies classified as youth involvement (19, 48). The search strategy is attached in the supplementary materials (Additional File 2).

Information sources

Electronic databases

We will search Cochrane Database of Systematic Reviews, Medical Literature Analysis and Retrieval System Online (MEDLINE), Scopus, Embase, PsycINFO, PsycArticles, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Epistemonikos, and Health Systems Evidence databases for potentially eligible reviews conducted up to 30th November 2021.

Grey literature search

The grey literature search involves several components. First, a simplified search strategy – based on different combinations of fewer key search terms – will be used to search Google Scholar for additional reviews. The Google Scholar search will be restricted to the first 10 pages. Second, we will identify the top 10 ranking pediatrics, perinatology, and child health journals using the Scimago Journal and Country Rank list for 2020 (17). A similar simplified version of the search strategy will be used to search these journals for additional reviews that could be potentially eligible for inclusion. Third, Web of Science and ProQuest will be searched to identify additional conference abstracts, theses, reports, and unpublished relevant reviews. The search strategy will be modified to suit the interface of these databases, as required. The search strategy for Web of Science is attached in the supplementary materials (Additional File 3). Fourth, we will search for relevant reviews registered on PROSPERO. Authors of potentially eligible reviews will be contacted to check whether the reviews are close to completion or have been completed. The authors will be requested to share the extracted data for inclusion in the umbrella review for complete or close to completion reviews. The number of contacts made and the number of authors who agreed to share the data will be recorded and reported. Fifth, websites of relevant organizations will also be searched for grey literature. This will involve compiling a list of organizations (including governmental, non-profit, and funding organizations) working on adolescents' health. We will conduct a targeted search of up to 20 pages of Google, the Mental Health Innovation Network (MHIN) database, and including organisations known to the authors. 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 will use the filter for age range to identify the organizations that work with young people. After identifying the organizations, we will search for relevant documents by running a simplified search strategy, like the one used for searching Google Scholar, on the website homepages of these organizations. The first ten pages of the results will be searched. Websites without a search option will be hand-searched. We will also search Google for youth health organizations in low- and middle-income countries and search the website of one organization (top google result) for each country. We will use World Bank's classification of countries to define low- and middle-income countries and DAC list of ODA recipients(98). We will only search the website of the organization that is the top google result for each of the 137 low- and middle-income countries to ensure at least one organisation from each country is included. Names of all organisational websites searched, and the titles and URL links to eligible materials will be extracted in the excel spreadsheet for grey literature, which will be posted on the review's Open Science Framework (OSF) page. Sixth, we will contact five to ten experts in youth involvement in health research. They will be regarded as an expert if, a) they oversee youth involvement in health research component at a funding organization (e.g., Wellcome Trust, Grand Challenges Canada) or youth health organization and/or, b) have conducted studies which involved adolescents as collaborators at different stages of the research process. We will include experts from high-, middle-, and low-income countries. After identifying potential experts to be contacted, we will send them an email stating the aims of the umbrella review, eligibility criteria for reviews, and a statement requesting that they share the references of any relevant materials they might be familiar with. Seventh, reference lists of all eligible reviews will be reviewed to identify further relevant reviews. Finally, all the eligible reviews will be entered in the connectedpapers software to identify similar papers. This

comprehensive strategy aims to identify all published and unpublished reviews on this topic and get the broadest range of views possible for inclusion in the umbrella review. The grey literature search will be conducted by AW.

Data management

All references from electronic databases will be exported to Covidence. We will record the search date, the number of results for each database and each combination of the search terms for grey literature search. For the grey literature, titles and URL links to potentially relevant documents will be entered in an excel spreadsheet for grey literature (99).

Eligibility Criteria

Study Design

Only review articles will be eligible for inclusion in this umbrella review. Although the Cochrane Overview of reviews guidelines recommend including systematic reviews and meta-analysis, we will include review articles of all types, including 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, as well as meta-analyses (100). This adaptation to the guidelines is due to the qualitative nature of the outcomes of interest and to ensure the inclusion of a wide range of literature on youth involvement. This adaptation to the guidelines is common in umbrella reviews focusing on qualitative data and outcomes (101).

Participants

We will only include reviews that discuss youth-specific results; the age range of participants in studies included in the review can vary, but the target population of the review must include

adolescents. Adolescents are young people between the ages of 10 to 24 years as defined by Sawyer et al. (97). All reviews focusing on children and adolescents irrespective of the age range (as long as these include some studies for adolescents aged between 10 and 24 years) will be included, but primary studies where the age range of the target population is below ten years or above 24 years will be excluded. Reviews and studies where the age range is not mentioned, rather the terms children and adolescents are listed will be included. No other restrictions will be applied based on demographic characteristics or context. 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 below in study selection section.

We are focusing on adolescents aged 10-24 for three reasons; i) this umbrella review aims to inform the development of a set of comprehensive guidelines on involvement of adolescents aged 10-24 to address the gaps in the currently available guidelines on involvement of adolescents in health research (19), ii) based on their developmental status, the methods used to engage children might be different than the ones used to engage adolescents therefore the recommendations for both age groups would vary, iii) logistical considerations including the additional time and resources required to develop recommendations on engaging children younger than 10 years.

Intervention

Reviews exploring youth involvement in studies that focus on the promotion of physical and mental health or treatment of physical and mental health difficulties among adolescents will be eligible. 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 broader than those of an

umbrella review, the umbrella review should only include primary studies from that review that meet the eligibility criteria for the umbrella review (94).

Youth involvement in health research refers to a wide range of methods and strategies used to involve young people in the design, conduct, analysis, and dissemination of research on adolescent health. Their involvement can range from consultation where young people are asked for advice and to share their views to inform decision-making (22), to collaboration which is characterised by "active, on-going partnership with young people" (22) and youth led research which involves "putting the locus of power, initiative and subsequent decision-making with young people" (22). This review will focus on all three levels of youth involvement in addition to all approaches to youth involvement.

Outcomes

Reviews including one or more of the following outcomes will be eligible for inclusion: i) strategies that have been used to involve adolescents in conducting health research, ii) recommendations for involving adolescents in health research (best practices), iii) barriers to meaningful youth involvement, iv) mitigation strategies to address these barriers and, v) evidence gaps in youth involvement in health research.

Other criteria

Only reviews published in the English language will be considered for inclusion. Reviews where data extraction tables for the primary studies (applicable to systematic, rapid, and scoping reviews) are inaccessible will be excluded. As per the Cochrane guidelines for overviews of reviews (94), if a review's research objectives and scope are broader than the current umbrella review, the subset of primary studies meeting the review's eligibility criteria will be included in this umbrella review.

Selection of studies

Search results will be imported into Covidence for the removal of duplicate references. The eligibility criteria will be discussed among researchers conducting the title and abstract screening to ensure mutual understanding of the criteria. Title and abstract screening of the studies will be undertaken by two postgraduate-level psychology students and an adolescent co-researcher. They will first conduct a pilot screening of 1% of randomly selected search results. Any discrepancies will be discussed and resolved before proceeding with title and abstract screening for the rest of the articles. AW will conduct the title and abstract screening of all articles, while co-researchers (QK) and an adolescent researcher will conduct title and abstract screening of 25% of articles to minimize the risk of bias. Where eligibility cannot be determined based on abstract, such articles will be labeled ambiguous and reviewed in full.

AW will conduct full-text screening and extract data from all eligible articles, while QK and an adolescent researcher will conduct full-text screening and data extraction for 10% of articles. Reasons for exclusion will be recorded for all excluded articles at this stage. Any discrepancies or disagreements will be resolved through discussion among these three researchers and, if required, through discussion with a fourth researcher (KH). The screening and study selection process will be reported in a PRISMA flow chart (102).

Overlap in primary studies across multiple reviews can give undue weightage to studies included more than once in the synthesis of findings. It is recommended to address the risk of overlap at the inclusion, data extraction, or synthesis stage (103). We will assess the overlap in primary studies at the data extraction and synthesis stage by creating a citation matrix (94, 104) where the primary studies will be cross-linked with the reviews they are included in. The reviews will be listed in columns, and the primary studies will be added in rows, with a tick mark added under all reviews

that include a primary study. The overlap will be quantified by calculating the corrected covered area measure (104) that indicates the degree of overlap. The citation matrix will help us ensure that the results of primary studies included in multiple reviews are only included once (103, 104). This citation matrix will be posted on the review's OSF page.

Data extraction

Data from the included reviews will be extracted using a data extraction form designed in Covidence. The data extraction form will be piloted by researchers extracting the data, using 1% of eligible full-text articles. Inter-rater reliability between the researchers will be assessed using the kappa statistic for the closedended fields of the data extraction form and risk of bias assessment. For open-ended data extraction fields, AW will compare the data extracted by all team members to assess whether a general agreement has been established on the data extraction process. Data on results will be extracted only from the included reviews. Data will be extracted on:

a) Characteristics of eligible reviews including review title, names and contact details of study authors, publication type (e.g., article, conference abstract, report, etc.), review type (scoping, narrative, systematic, etc.), the age range of study population in the review, the condition under study (e.g., physical health, mental health, or specific disease/disorder), aim of the review, definition of youth involvement used, search strategy, databases and grey literature sources searched, search end date, method of synthesis, and tool used to appraise the risk of bias for the primary studies.

b) Characteristics of primary studies include their eligibility criteria, the number of primary studies included in the review, the study design of primary studies, and the risk of bias results for the primary studies.

c) Findings will consist of the use of different youth involvement strategies, level of youth involvement, challenges, or barriers in the use of youth involvement strategies, recommendations to address these barriers, best practices in youth involvement in health research, limitations of the review, and gaps identified in the literature.

Risk of bias assessment

A MeaSurement Tool to Assess systematic Reviews-2 (AMSTAR 2) (105) will be used to assess the methodological quality of included systematic reviews. The risk of bias assessments conducted for the primary studies in the included reviews will be narratively summarized. AW will conduct the risk of bias assessment of all eligible systematic reviews, while a second reviewer will conduct the risk of bias assessment for 10% of eligible systematic reviews. Any discrepancies or disagreements will be resolved through discussion among these two researchers and, if required, through discussion with a third researcher (KH).

Narrative synthesis

A narrative synthesis will be conducted by AW and a youth co-researcher to analyse the data. The first step will include familiarization with the extracted data through close reading, followed by coding the extracted data using deductive coding. Then, the codes will be structured under broader themes. Finally, these themes will be summarised in a descriptive and tabular form, centred around the research aims and objectives. AW and a youth co-researcher will analyse a subset of the data together until there is a general agreement on the coding and narrative building.

Patient and Public Involvement

Adolescents will be involved in the title and abstract screening, full-text screening, data extraction, analysis, and dissemination phases of this umbrella review. These adolescents will be invited to

participate through local non-profit organizations and/or academic institutions. Specifically, the youth co-researchers and co-authors DB, ML, and PC reviewed the final protocol for the umbrella review and shared their input. An adolescent co-researcher will be recruited to conduct title and abstract screening for 25% of the articles and undertake full-text screening and data extraction for 10% of articles to ensure representation of youth in decision-making processes. Another youth co-researcher will contribute to the data analysis by working with AW to develop themes and write up the narrative synthesis. To increase the relevance of the findings, we will seek input from 6-8 members of a youth advisory group in two participatory workshops. In the first workshop, young people will be invited to share their interpretation of the results and reflections on the challenges and recommendations highlighted in the literature. In the second workshop, they will contribute by reviewing the outputs of this umbrella review and ensuring the language used is accessible and inclusive. We will also facilitate the young co-researchers and advisors to present the findings to the scientific community via video abstracts and to youth and lay audiences through dissemination methods determined by the youth themselves to ensure more effective and wider dissemination of the results. Youth co-researchers will also help us recruit youth advisors for the review. Previous experience of research will not be a criterion for youth co-researchers to be engaged in this project.

Discussion

This review will bring together evidence on the most effective ways of involving adolescents in health research, challenges experienced in this process, and mitigation strategies which have been recommended to address or prevent these challenges. These findings will inform the development of guidelines on involving adolescents in health research. The need for a comprehensive set of guidelines and resources on involving adolescents in health research has been highlighted by youth researchers (81) and studies (83, 106-109). These guidelines will facilitate researchers to

collaborate with adolescents more effectively, leading to more meaningful involvement of adolescents in research.

This umbrella review has a few limitations. The search for eligible reviews will be restricted to the English language. Additionally, while the search strategy incorporates a wide range of terms to account for the variation in terminology around youth involvement, there is a possibility that relevant reviews indexed using different terms will not be included. Moreover, umbrella reviews are based on the information presented in the review articles and are therefore limited by the quality of extracted data in the included reviews. There is also a possibility of missing relevant data on youth involvement in health research that has not previously been included in reviews. This review only focuses on involvement of adolescents aged 10-24 in health research therefore the findings of the review will not be generalisable to children younger than 10 years. Given the focus on adolescent involvement in health research, any relevant guidance on engaging young people based on research in other disciplines and fields may be excluded. Any deviations to the submitted protocol will be documented as amendments to the PROSPERO registration.

Ethics and dissemination: Only reviews will be included in this umbrella review; therefore, ethical approval is not required. The findings of this umbrella review will be disseminated through peer-reviewed publications, participatory workshops, and academic conferences.

Supplementary Information

Additional file 1. PRISMA-P Checklist.

Additional file 2. Search strategy for MEDLINE

Additional file 3. Search strategy for Web of Science

Competing interests

The authors declare that they have no competing interests.

Funding statement

Azza Warraitch received the Ussher Fellowship from Trinity College Dublin to support her PhD research, including this umbrella review. She received a Trinity Research in Social Sciences (TRiSS) Research Fellowship to conduct participatory workshops with youth as part of this umbrella review. The funders did not play any role in design of this review.

Authors' contributions

AW and KH conceptualized and wrote the protocol with valuable inputs from QK. DB, ML, PC will contribute to the screening, data extraction and analysis of this review as young co-researchers. All authors have reviewed and approved the final manuscript.

Acknowledgments

We would like to acknowledge all members of the Trinity Centre for Global Health and School of Psychology – especially Drs Sadhbh Byrne, Frédérique Vallieres, and Elizabeth Nixon – for their valuable inputs. We would also like to thank Ms. Geraldine Fitzgerald, the research librarian at the School of Medicine, Trinity College Dublin, for her feedback and input on the search strategy for this umbrella review. We are very grateful to all the youth advisors and co-researchers who contributed to this project.

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PRISMA-P 2015 Checklist

This checklist has been adapted for use with systematic review protocol submissions to BioMed Central journals from Table 3 in Moher D et al: Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* 2015 **4**:1

An Editorial from the Editors-in-Chief of *Systematic Reviews* details why this checklist was adapted - Moher D, Stewart L & Shekelle P: Implementing PRISMA-P: recommendations for prospective authors. *Systematic Reviews* 2016 **5**:15

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
ADMINISTRATIVE INFORMATION					
Title					
Identification	1a	Identify the report as a protocol of a systematic review	☒	☐	1-2
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	☐	☒	
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract	☒	☐	37
Authors					
Contact	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	☒	☐	6-12
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	☒	☐	436-439
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	☐	☒	
Support					
Sources	5a	Indicate sources of financial or other support for the review	☒	☐	431-435
Sponsor	5b	Provide name for the review funder and/or sponsor	☒	☐	431-435
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	☒	☐	435
INTRODUCTION					
Rationale	6	Describe the rationale for the review in the context of what is already known	☒	☐	129-174

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	☒	☐	170-174
METHODS					
Eligibility criteria	8	Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review	☒	☐	260-317
Information sources	9	Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage	☒	☐	199-254
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	☒	☐	Additional file 2 and 3
STUDY RECORDS					
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	☒	☐	255-259
Selection process	11b	State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis)	☒	☐	261-286
Data collection process	11c	Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	☒	☐	318-344
Data items	12	List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications	☒	☐	318-344
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	☒	☐	318-344
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	☒	☐	367-374
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	☐	☒	
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., I^2, Kendall's tau)	☐	☒	
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-	☐	☒	

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
		regression)			
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	☒	☐	375-381
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)	☐	☒	
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)	☐	☒	

Search strategy for MEDLINE

#	Query	Limiters/Expanders
S17	S3 AND S8 AND S15 AND S16	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S16	AB review OR TI review	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S15	S13 OR S14	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S14	S9 OR S10 OR S11 OR S12	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S13	Involv* OR "advisory group*" OR "research advisory group" OR "research advisory panel*" OR "advisory panel" OR "advisory committee*" OR "advisory board*" OR "youth engagement" OR "patient and public involvement" OR "public and patient involvement" OR "public patient involvement" OR "community based participatory research" OR "youth particip*" OR "adolescent engagement" OR "participatory design" OR "participatory action" OR "needs assessment*" OR "co produc*" OR "co design" OR "Human centered design" OR "Human centred design" OR "User centered design" OR "User centred design" OR "user involvement" OR "peer researcher*" OR "co researcher*" OR "Patient Participation" OR "young researcher*" OR "lived experience"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S12	(MM "Community Participation+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S11	(MM "Community-Based Participatory Research+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S10	(MM "Patient Participation")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S9	(MM "Stakeholder Participation+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S8	S4 OR S7	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S7	S5 OR S6	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S6	(MM "Young Adult")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S5	(MM "Adolescent")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

S4	AB (child* OR youth OR adolescen* OR "young people" OR "Young person*" OR "Young adult*" OR teen* OR juven*) OR TI (child* OR youth OR adolescen* OR "young people" OR "Young person*" OR "Young adult*" OR teen* OR juven*)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S3	S1 OR S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S2	AB "health research" OR TI "health research"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase
S1	(MM "Health Services Research+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

Search strategy for Web of science

(((TS=(review)) AND TS=(“Health research”)) AND TS=(child* OR youth OR adolescen* OR "young people" OR "Young person*" OR "Young adult*" OR teen* OR juven*)) AND TS=(Involv* OR "advisory group*" OR "research advisory group" OR "research advisory panel*" OR "advisory panel" OR "advisory committee*" OR "advisory board*" OR "youth engagement" OR "patient and public involvement" OR "public and patient involvement" OR "public patient involvement" OR "community based participatory research" OR "youth particip*" OR "adolescent engagement" OR "participatory design" OR "participatory action" OR "needs assessment*" OR "co produc*" OR "co design" OR "Human centered design" OR "Human centred design" OR "User centered design" OR "User centred design" OR "user involvement" OR "peer researcher*" OR "co researcher*" OR "Patient Participation" OR "young researcher*" OR “lived experience”)