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Collaborative research methods and best practice with children and young people: Protocol for a mixed-method review of the health and social sciences literature

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3 Collaborative research methods and best practice with children and young people: Protocol
4 for a mixed-method review of the health and social sciences literature
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Abstract

Introduction

Children and young people have the right to participate in research on matters that affect them, and their contribution improves research quality and insights from findings. Discrete participatory approaches are used across different disciplines. This review will provide a synthesis of existing literature from different disciplines by working with young people and adults experienced in participatory research to develop a broad definition of child and youth led research and to identify best practice.

Methods and Analysis

Comprehensive searches will be conducted in eight electronic databases (PsycINFO, Medline, CINAHL, Embase, SocINDEX, ASSIA: Applied Social Sciences Index and Abstracts (Proquest), Social Care Online and SCOPUS). Grey literature reports will also be sourced using Google searching. Eligible studies will be English language primary studies and reviews on collaborative research with children and young people (aged 5-25 years). Qualitative and quantitative data will be integrated in a single qualitative synthesis following the JBI convergent integrated approach. Study quality will be assessed by developed checklists based on existing participation tools co-created with the project steering group and co-creation activities with young people.

Ethics and Dissemination

Ethical approval is not required as no primary data will be collected. The review will develop guidance on best practice for collaborative research with children and young people, synthesising learnings from a wide variety of disciplines. Dissemination will be via peer-reviewed publications, presentations at academic conferences and lay summaries for various stakeholders. Opportunities for co-creation of outputs will be sought with the young researchers and the project steering committee.

PROSPERO registration number: CRD42021246378

Key words: peer research; patient and public involvement; children; young people; youth participatory action research; YPAR

Article Summary

Strengths and limitations of the study

- First systematic review to synthesise findings across different approaches to collaborative research with children and young people
- Research focus, questions and analysis framework have been co-designed with young researchers experienced in participatory research
- Mixed method review methodology will enable an in-depth evidence synthesis across a disparate evidence base
- Provides an interdisciplinary perspective on best practice for collaborative research with children and young people

For peer review only

Introduction

It is widely acknowledged that children and young people have the right to participate in research on matters that affect their lives, and that their contribution to research adds value to the research processes and outcomes. Involving children and young people as partners in the research process improves research design and refines research priorities, increases the accessibility and attractiveness of research methods and ensures that children and young people's perspectives are represented in analysis and outputs providing fresh insights and recommendations based on their lived experience.¹ The right to participate in research is implicit in the 1989 United Nation's Convention on the Rights of the Child.² It is articulated explicitly in the 2012 Council of Europe Recommendation on Children's Participation³ which notes that member states (including the UK) should:

stimulate research on, with and by children and young people, with a view to enabling better understanding of the views and experiences of children and young people, identifying obstacles to their participation and ways of overcoming them (3p9)

The paradigm shift from 'research on' to 'research with and by children and young people' is of particular significance here as it covers approaches to health and social research that may be called 'participatory', in which children and young people take a greater or lesser lead in empirical studies. Increasingly research funders (e.g. Economic Social Research Council, National Institute for Health Research (NIHR)) are expecting children and young people to be research advisors and/or co-researchers, with statements of patient and public involvement being required in funding applications. For example, NIHR in their UK ten year plan for patient and public involvement and engagement published in 2015 commit to having "a population actively involved in research to improve health and wellbeing for themselves, their family and their communities" and the "public as partners in everything we do".⁴ Since 2012, a number of systematic or mapping reviews have been conducted on participatory research, however apart from reviews by Rouncefield-Swales¹ and Wilson et al.⁵ - which focus on health research - there has not been a synthesis involving different disciplines on participatory research in which children or young people collaborate with adult researchers and/or take a lead in particular aspects of the research. This review co-produced with young people and adults experienced in participatory research, develops a broad definition of collaborative research with children and young people (i.e. children and/or young people explicitly involved in at least one stage of the research process beyond just generating data and involvement in dissemination or recruitment of participants). It draws on learning from different disciplines/approaches, including Youth Participatory Action Research (YPAR), public and patient engagement, citizen science, community-based peer research and some forms of collaborative research with children and young people.

As mentioned, involving children and young people as collaborators in the research process not only impacts on research design and quality but it can also produce creative and situated forms of 'learning in action' (6p359) as well as 'reflexive processes of social engagement' (6p359), which create new spaces for generating and using knowledge.⁶ However, achieving these potential benefits is known to be challenging as it can be hard to ensure that power is distributed, that children and young people's perspectives are valued, and that research is clearly linked into effective strategies for achieving personal and social change.⁷⁻¹⁰ There continues to be a need for more guidance, particularly on collaborating with marginalised children and young people in ways that enables them to genuinely lead.¹¹

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3 In addition to being left out of knowledge production in the ways that adults experience (due
4 to the intersections of 'race', ethnicity, gender, class, sexuality and disability), children and
5 young people who experience discrimination through intersecting social ontologies, social
6 categories and social relations face further marginalisation in research.¹² The exclusion of
7 children and young people is pervasive due to dominant conceptions of children and young
8 people as an homogenised social category represented as incompetent, vulnerable, politically
9 immature and needing the completion of education in order to deserve recognition as citizens
10 and as competent researchers.¹³ Young people are often conceived of as apathetic or
11 troublemakers, rather than recognising how young people are alienated by neo-liberal practices
12 .¹⁴ The battle over what counts as evidence¹⁵ can also render children and young people's
13 perspectives and sometimes their chosen means of expression, less valid than scientific
14 orthodoxy.
15
16

17
18 Where children and young people are included in research, they may be provided with
19 information, or experience being 'researched on', however their influence over the priorities to
20 investigate, and changes in guidance and practice is poorly evidenced. In 1999, Pole et al¹⁶
21 noted that, despite the turn towards participatory methods across multiple disciplines, children
22 and young people do not have enough research capital to make them serious stakeholders in
23 the research process. Brownlie⁷ repeated this, echoing the concern that "children and young
24 people remain a long way from the emancipatory call of 'nothing about us, without us'"(7p711).
25 And still, a decade on, Lohmeyer⁸ repeats that "In theory, youth participatory methods are
26 participant-led, and adults are involved in the process. However, there are social, historical,
27 procedural and institutional barriers that make this ideal all but unachievable"(8p44). This is
28 despite the fact that some young people are "keen as f**k" to participate.⁸
29
30

31
32 Unless these barriers to collaborative research with children and young people are fully
33 understood and strategies for overcoming the challenges are shared, research risks being
34 perpetuated as yet another form of symbolic violence.^{17 18} That is, it will create conditions
35 which perpetuate and normalise children and young people's subordinate position in processes
36 of knowledge creation. Or, peer-led research may become a mechanism through which
37 children and young people are exploited as lower paid or unpaid labour, to access young
38 communities who are suspicious of mainstream health and social science research without
39 allowing them power to identify what issues need investigating. There is therefore need for
40 greater attention to the precise mechanisms, methods and reflexive stances which enable
41 children and young people to lead research.¹⁸
42
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44
45 Questions remain, however, about the kind of knowledge that is generated by collaborative
46 research methods and attention to what we mean by concepts such as knowledge and
47 epistemology. Young researchers cocreate methods, including digital methods¹⁹, photo-
48 walks²⁰, map-making²¹ and storytelling²² which extend beyond traditional methods. Young
49 researchers highlight that these methods are experienced positively by research participants²³
50 ²⁴ and hence these co-creative approaches acknowledge shared responsibilities and skills in
51 health and social research.²⁵ But these methods are not always valued by end users of research
52 outputs, resulting in biases towards research that is not always congruent with children and
53 young people's interests, concerns and contexts. Policy actors, funders and commissioners
54 may need greater awareness of a diversity of approaches to rigour, quality and impact²⁶, and
55 may need to extend their understanding of health and social research to also recognise the
56 validity that arises from greater degrees of participation.²⁷ Evidence that can demonstrate how
57 the knowledge from collaborative research with children and young people can be valued by
58 and acted on by decision-makers may therefore provide further benefits.
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What is needed is a synthesis of epistemologies and methodologies across a broad range of different disciplines to establish key contexts for successful research by and with children and young people. The current review addresses this gap by establishing precise mechanisms, methods and reflexive stances which enable children and young people to lead and collaborate as partners in research identifying best practice from existing evidence. The review will inform both researchers and policy actors, funders and commissioners of the diversity of approaches that may be appropriate to enable collaborative research with children and young people whilst maintaining academic rigour and quality. Barriers and challenges will be highlighted to ensure power imbalances are addressed and ways of working with marginalised groups will be identified. The review will be useful to guide future collaborative research with children and young people but will also identify key gaps in the evidence base where future work needs to be conducted.

Aim of the review

To identify theoretical principles and practice modes and mechanisms of effective collaborative research with children and young people in the field of health and social sciences, that are generalisable as a basis for designing effective peer research projects, protocols and establishing best practice.

The mixed methods review will scope and synthesise existing knowledge about best practice in conducting collaborative research with children and young people using the following research questions co-created with young people and adults experienced in participatory research:

1. What are the opportunities, barriers and tensions in youth peer research and how can these be understood and addressed?
2. What are the different modes and mechanisms of doing peer research? Which of these are valued, by whom, in which contexts and why?
3. How is success, impact and change documented, understood, negotiated and evaluated in peer research?

Question 1 focusses specifically on issues identified by young people experienced in participatory research as critical involving *cushions* (e.g. negotiated support with tasks, skills, decision making and managing the emotional impact of conducting research), *credibility*, *collaboration* and *change*. More detailed sub-questions have been devised to address these highlighted issues:

- a) How do young and adult researchers ensure that young researchers have the *cushions* they want throughout the research process?
- b) Which processes and structures ensure *collaborative* peer research is acceptable and accessible to the diversity of children and young people (age, identity, experience of discrimination, economic situations)?
- c) How can we ensure that peer research is maximised in terms of strengthening claims to knowledge and *credibility*, conveying convincing stories, linking to current opportunities and minimising risk of negative attention?

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3 d) Which processes and/or structures help ensure productive relationships between
4 stakeholders, allies, contexts and resources to support the use of evidence to make
5 *change* possible?
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8 Ethics, safety, inclusion and power as themes relating to peer research will be considered across
9 all research questions. We will also report on the topics into which peer research has been
10 conducted and examine differences in modes, mechanisms and success across different topics.
11
12

13 **Methods and Analysis**

14
15 This protocol is guided by the Preferred Items for Reporting of Systematic Reviews and Meta-
16 Analyses Protocols (PRISMA) checklist²⁸ (online supplemental appendix 1) and the Joanna
17 Briggs Institute (JBI) methodology for mixed-methods systematic reviews.²⁹
18
19

20 **Study registration**

21
22 Based on the PRISMA guidelines²⁸, the protocol for this systematic review was registered on
23 the international database of prospectively registered systematic reviews in health and social
24 care, PROSPERO. Any important protocol amendments will be recorded in PROSPERO and
25 published with the results of the review.
26
27

28 The mixed methods review will involve: 1) a systematic review of reviews on peer research
29 and 2) realist synthesis of process and descriptive papers defined as those describing lessons
30 learnt or a description of the programme, process or training of a peer model and articles that
31 focused on the peers themselves and their experiences within a peer model/approach
32 (distinction from Vaughn et al.³⁰).
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35 The systematic review of reviews will identify and establish the core models and methods used
36 in collaborative research with children and young people and the realist synthesis will offer a
37 more nuanced understanding of what works in peer research, for whom, in what contexts and
38 why. Findings will be triangulated and used to develop a critical appraisal tool to assess peer
39 research.
40
41

42 **Eligibility criteria**

43
44 Studies and reviews will be selected according to the criteria set out below:
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46

47 **Types of studies**

48
49 We will include systematic and scoping reviews, descriptive and process papers (using the
50 distinction made by Vaughn et al.³⁰) relating to peer research, including also grey literature
51 reviews/reports. We will exclude papers that are exclusively empirical papers without
52 description of process or reflections, dissertations, editorials, opinion pieces, commentaries,
53 book or movie reviews, protocols, reports, case studies and erratum. We will only include
54 studies about peer research with children and young people. We will exclude studies
55 examining peer research in adult populations. Only studies written in English will be included
56 and those published after 2000 (due to the exponential growth in young people's involvement
57 in social research from 2000 onwards).
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3 We will use a wide definition of peer research and include all reviews and process/descriptive
4 papers including a wide range of terms used to describe peer research (i.e. participatory
5 research, YPAR, community-led research, peer research informed social action etc.).
6
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8 Participants

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10 We will include peer research involving children and young people (aged 5-25 years) and
11 exclude peer research conducted with adults. Articles about research with primary school aged
12 children will be included to extrapolate potentially generalisable findings on peer research to
13 an older population of children and young people, but we will be mindful of differences in
14 developmental stages and needs.
15

16
17 Peer research (including community-based participatory research, peer led research, youth
18 inquiry, co-production, citizen science, youth participatory action research, peer research
19 informed social action).
20

21 Outcomes

22
23 Theoretical principles, practice and mechanisms and findings in relation to power, inclusivity,
24 ethics, safeguarding, learning, methods, and impact.
25

26
27 We report on other important or critical factors and influencers of best practice in peer research
28 highlighted by selected papers.
29

30 Search strategy

31
32 We recruited a review steering group involving participants from Youth Endowment Fund,
33 study partners, appointed advisors and experienced young researchers from marginalised
34 groups, academics experienced in youth participation and relevant third sector professionals
35 and policy actors. Online discussions with this group (n = 18) were held in the form of a week-
36 long civic hackathon⁽³¹⁾; creative problem-solving sessions conducted once a day (1 ½ hours
37 long) for a full week in March 2021) involving activities to enable:
38
39

- 40 • Reflection and sharing of ideas about key concepts and challenges in peer research
- 41 • Reflection and definition of a proportionate systematic approach and relevant inclusion
42 criteria
- 43 • Agreement of research questions, inquiry themes and focus for the review
44
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46
47 The findings from the online hackathon informed the focus of the research, search strategy,
48 inclusion and exclusion criteria and framework for synthesis.
49

50
51 In addition, we conducted a priori scoping searches to identify key review papers in this specific
52 research area which also informed our search strategy.
53

54 We will use the Preferred Reporting Items for Systematic Review and Meta-Analysis checklist
55 (PRISMA;³²) as a framework for the review.
56

57 We plan to conduct searches on eight bibliographic databases:
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3 PsycINFO, Medline, CINAHL, Embase, SocINDEX, ASSIA: Applied Social Sciences
4 Index and Abstracts (Proquest), Social Care Online and SCOPUS
5

6 Handsearching will also be used, involving forward and backward chaining and examination
7 of references lists from reviews and key papers in this research area. We will also check
8 author's personal files for any key studies. In accordance with PRISMA guidelines³², the
9 number of search results will be recorded at each stage of the study identification process. In
10 order to locate wider reviews on peer research that have been conducted we will include grey
11 literature reports, which will be obtained through Google searching using the key words (first
12 200 hits will be screened).
13
14

15
16 The following search terms have been developed following a priori scoping exercises and
17 online forum exercises with experienced young peer researchers and stakeholders:
18

19 (Child/ or Adolescent/ or child or children or kid or kids or girl* or boy* or adolescen*
20 or teen* or Youth* young people or young adult or young person or young men or
21 young women)
22

23
24 AND

25
26 Community-based participatory research/ or participatory research* or participatory
27 method* or participatory approach* or participatory design or participatory model* or
28 user led research or peer led research or peer research* or consumer led research or
29 action research or youth inquir* or co-produc* or coproduc* or co-research or
30 coresearch or co-creation or cocreation or co-design* or codesign* or co-develop* or
31 codevelop* or co-investigator* or coinvestigator* or citizen science or citizen scientist
32 or YPAR or advisory group* or advisory council or youth participation or young
33 involved or child led research* or peer model or research partner or social action)
34
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36 The search strategy will be adapted to meet the truncation and Boolean operations of each
37 database as appropriate. An example of the search strategy used for Medline database is
38 presented (online supplemental appendix 2).
39
40

41 **Study Selection**

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43 Papers identified from database searches will be downloaded to Endnote and any duplicates
44 removed. Screening by title and abstract will be conducted in Rayyan independently by one of
45 the authors, with at least 20% of the papers screened by another author. Decisions will be based
46 on the inclusion and exclusion criteria.
47
48

49 Once screening by title and abstract is complete, papers selected for full text screening will be
50 sourced and then examined by one author independently, with at least 20% of the papers
51 screened by another author. Reasons for exclusion will be noted at this stage.
52
53

54 Agreement at all stages will be made by consensus, and any disagreements regarding inclusion
55 will be discussed with a third reviewer. Inter-rater reliability will be recorded at each screening
56 stage (i.e. title, abstract and full text screening).
57
58

59 **Data extraction**

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3 Following screening, data will be extracted from all selected texts using a data extraction sheet
4 with a framework developed and co-created with the steering group. As suggested by Daudt,
5 van Mossel, and Scott³³ (2013) at least 20% of data extracted will be charted by two authors
6 independently using the data extraction tool. Once sufficient agreement (> 80%) has been
7 reached in the test phase, authors will apply the tool to the remaining studies. Disagreements
8 between the authors completing the data extraction will be resolved through discussion,
9 including the involvement of a third reviewer where necessary. It is expected that data
10 extraction will include key study characteristics, participant characteristics, definitions of peer
11 research, models and mechanisms (focussing specifically on research approaches and
12 processes identified in hackathon activities) relationships, attitudes, approaches, resources,
13 distribution of leadership, timescales, and change) and co-created frameworks based on
14 identified challenges and tensions in peer research centred on *cushions*, *credibility*,
15 *collaboration* and *change*. We will also chart any other important or critical factors and
16 influencers of best practice in peer research highlighted within selected papers.
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21 During the data extraction stage, the research team will meet on a regular basis to discuss
22 progress, and to consider decisions regarding the relevance and adequacy of the data collection
23 tool. Those discussions will be documented along with any changes to the study protocol and
24 data extraction. Study authors will be contacted if additional information is required (e.g.
25 context related details of the study).
26

27 **Assessment of Methodological Quality**

28
29 Two authors will independently assess the research quality and bias of each of the included
30 articles involving studies of peer research using developed checklists based on existing
31 participation tools (e.g. Larkins et al.'s Participation Lattice³⁴; Shier's analytical tool³⁵) co-
32 created with the steering group and based on the results of activities in the hackathon.
33 Discrepancies between the review authors will be resolved by discussion, consulting a third
34 review author where necessary.
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37
38 Two authors will independently assess the research quality and bias of all the review studies
39 on peer research included using the AMSTAR 2 Appraisal Tool³⁶ for systematic reviews. Inter-
40 rater reliability will be reported and any discrepancies between authors will be resolved through
41 discussion or where necessary a third author will be consulted.
42
43

44 **Data synthesis**

45
46 Data extracted will be collated, summarised and synthesised narratively. Data will be presented
47 as tables, charts and/or visual maps in an aggregate rather than individual basis, to provide an
48 overview of the research field, summarise findings, identify gaps in the literature and make
49 recommendations for future research. Data analysis will be conducted in two phases: 1)
50 narrative synthesis of theoretical principles (i.e. definitions of peer research) and
51 mechanisms/methods used and 2) analysis of findings around the co-produced thematic
52 framework *cushions*, *credibility*, *collaboration* and *change* and 3) content and thematic
53 analysis using a co-created approach realist framework. We will explore youth characteristics
54 and contextual factors that influence what works for peer research with young people.
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Patient and Public Involvement statement

The public were involved from the very start of developing the protocol. Young researchers and non-academic third sector professionals (service providers and funders) took part in a series of online discussions with academics. This was framed as a civic hackathon³¹, that is a series of online events held in quick succession, with the aim of identifying what is currently understood by the term peer research by and with children and young people, to explore the challenges and potential of these approaches and to create a set of questions to guide the review. Four online events were conducted, of around 90 minutes each, to frame the review. The events were facilitated by senior academics experienced in participatory research with young people. We used visual aids and online scribing to elicit the perspectives of young people and adults experienced in participatory research and then guest academics were asked to respond to this. At the end of every meeting we created a 3 minute summary of key discussion points and perspectives and shared this, along with the visual and text notes of the meeting, to support the participation of those who could not attend on specific days. Contributors to these non-synchronous discussions tended to be academics. At the start of every meeting we reviewed the story of our discussions so far, and summarised content that had been provided in between meetings. At the end of the third meeting, ideas generated to date were used to draft initial questions for the review. These were amended and finalised at the fourth meeting.

Whilst the review has been underway a further two online events have been held to discuss emerging findings and potential outputs and a further four events are planned to enable young researchers to contribute to at least one accessible output (an audio podcast has been planned) and all academic articles. Young people have decided that the podcast will be shared on an open access platform codesigned by young researchers for young researchers. All participants in these activities either contributed as part of paid roles or received a thank you in the form of vouchers.

Ethics and Dissemination

Ethical approval and consent to participate are not required for the proposed systematic review as no primary data will be collected. The findings of the mixed methods review will be written up as a report which will directly inform peer research training for the Peer Research and Social Action Network, funded by the Youth Endowment Fund together with the #iwill Fund and the Co-op Foundation. The Peer Research and Social Action Network will support young people affected by violence to become Peer Researchers and Changemakers. We will also explore opportunities with youth peer researchers to co-create accessible outputs to be disseminated through peer research networks. We expect that the findings will be written up in peer reviewed academic journals as a systematic review of reviews, realist synthesis reviews of papers about processes of peer research, and intergenerational reflections on the review process.

Authors Contributions:

CL is the guarantor. RN and CL drafted the manuscript. All authors contributed to the development of the selection criteria, the risk of bias assessment strategy and data extraction criteria. RN, CL and CH developed the search strategy. CL, LR, DS, and AR provided expertise on peer research with children and young people. RN and LR provided expertise on systematic review methodology. All authors read, provided feedback and approved the final manuscript.

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Competing interests statement:

None declared.

Data statement:

Datasets (i.e. data extraction charts and analyses) will be available from the University of Central Lancashire's online repository (CLOK).

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For peer review only

PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol*

Section and topic	Item No	Checklist item	Page 1
ADMINISTRATIVE INFORMATION			
Title:			
Identification	1a	Identify the report as a protocol of a systematic review	1,7
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	n/a
Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number	2
Authors:			
Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author	1
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	11
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	n/a
Support:			
Sources	5a	Indicate sources of financial or other support for the review	12
Sponsor	5b	Provide name for the review funder and/or sponsor	12
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	12
INTRODUCTION			
Rationale	6	Describe the rationale for the review in the context of what is already known	4-6
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	6-7
METHODS			
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	7-8
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage	8-9
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	8-9

Study records:			
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	9
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)	9
Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), 10 any processes for obtaining and confirming data from investigators	10
Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications	10
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	10
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	10
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised	10
	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 (such as I ² , Kendall's τ)	n/a
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)	n/a
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	10
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)	10
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)	10

*** It is strongly recommended that this checklist be read in conjunction with the PRISMA-P Explanation and Elaboration (cite when available) for important clarification on the items. Amendments to a review protocol should be tracked and dated. The copyright for PRISMA-P (including checklist) is held by the PRISMA-P Group and is distributed under a Creative Commons Attribution Licence 4.0.**

From: Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart L, PRISMA-P Group. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. BMJ. 2015 Jan 2;349(jan02 1):g7647.

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3 Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-
4 Indexed Citations and Daily <1946 to March 09, 2021>

5 Search Strategy:
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9 1 Child/ (1723917)
10 2 Adolescent/ (2073420)
11 3 (child or children or kid or kids or girl* or boy*).tw. (1403418)
12 4 (adolescen* or teen* or youth\$1).tw. (355741)
13 5 (young adult* or young person or young people).tw. (126562)
14 6 or/1-5 (3516212)
15 7 Community-Based Participatory Research/ (4691)
16 8 (participatory adj (research* or method* or approach* or design* or model*)).ti,ab,kw,kf.
17 (6848)
18 9 (user led research or peer led research or peer research* or consumer led research or action
19 research or youth inquir*).ti,ab,kw,kf. (4670)
20 10 (co-produc* or coproduc* or co-research* or coresearch* or co-creation or cocreation or co-
21 design* or codesign* or co-develop* or codevelop* or co-investigator* or
22 coinvestigator*).ti,ab,kw,kf. (8598)
23 11 (citizen science or citizen scientist*).ti,ab,kw,kf. (1505)
24 12 (YPAR or ((youth or young or patient) adj2 (advisory group* or advisory
25 council*))).ti,ab,kw,kf. (153)
26 13 (youth adj2 (involvement or participation)).tw. (683)
27 14 or/7-13 (23743)
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BMJ Open

Collaborative research methods and best practice with children and young people: protocol for a mixed-method review of the health and social sciences literature

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2022-061659.R1
Article Type:	Protocol
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Keywords:	Community child health < PAEDIATRICS, Child & adolescent psychiatry < PSYCHIATRY, PUBLIC HEALTH, QUALITATIVE RESEARCH, SOCIAL MEDICINE, STATISTICS & RESEARCH METHODS

SCHOLARONE™
Manuscripts

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3 **Collaborative research methods and best practice with children and young people:**
4 **protocol for a mixed-method review of the health and social sciences literature**
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Abstract

Introduction

Children and young people have the right to participate in research on matters that affect them, and their contribution improves research quality and insights from findings. Discrete participatory approaches are used across different disciplines. This review will provide a synthesis of existing literature from different disciplines by working with young people and adults experienced in participatory research to develop a broad definition of child and youth led research and to identify best practice.

Methods and analysis

Comprehensive searches will be conducted in eight electronic databases (PsycINFO, Medline, CINAHL, Embase, SocINDEX, ASSIA: Applied Social Sciences Index and Abstracts (Proquest), Social Care Online and SCOPUS). Grey literature reports will also be sourced using Google searching. Eligible studies will be English-language primary studies and reviews on collaborative research with children and young people (aged 5-25 years) published from 2000 onwards. Qualitative and quantitative data will be integrated in a single qualitative synthesis following the JBI convergent integrated approach. Study quality will be assessed by developed checklists based on existing participation tools co-created with the project steering group and co-creation activities with young people.

Ethics and dissemination

Ethical approval is not required as no primary data will be collected. The review will develop guidance on best practice for collaborative research with children and young people, synthesising learnings from a wide variety of disciplines. Dissemination will be via peer-reviewed publications, presentations at academic conferences and lay summaries for various stakeholders. Opportunities for co-creation of outputs will be sought with the young researchers and the project steering committee.

PROSPERO registration number: CRD42021246378.

Keywords: peer research; patient and public involvement; children; young people; youth participatory action research; YPAR

Strengths and limitations of this study

- Research focus, questions and analysis framework have been co-designed with young researchers experienced in participatory research.
- Primary screening of the articles, data extraction and quality assessment will be performed independently by two persons to minimise the probability of personal biases.
- Mixed method review methodology will enable an in-depth evidence synthesis across a disparate evidence base.
- Databases in languages other than English (French, German, Chinese, etc) will not be searched or included which may cause language bias.
- There are limited critical appraisal tools to assess quality of co-created evidence bases that do not met the conventional standards.

Introduction

It is widely acknowledged, across health and social sciences, that children and young people have the right to participate in research on matters that affect their lives, and that their contribution to research adds value to the research processes and outcomes. Involving children and young people as partners in the research process improves research design and refines research priorities, increases the accessibility and attractiveness of research methods and ensures that children and young people's perspectives are represented in analysis and outputs providing fresh insights and recommendations based on their lived experience.¹ The right to participate in research is implicit in the 1989 United Nation's Convention on the Rights of the Child.² It is articulated explicitly in the 2012 Council of Europe Recommendation on Children's Participation³ which notes that member states (including the UK) should:

stimulate research on, with and by children and young people, with a view to enabling better understanding of the views and experiences of children and young people, identifying obstacles to their participation and ways of overcoming them (3p9)

The paradigm shift from 'research on' to 'research with and by children and young people' is of particular significance here as it covers approaches to research that may be called 'participatory', in which children and young people take a greater or lesser lead in empirical studies. Increasingly research funders (e.g. Economic Social Research Council, National Institute for Health Research (NIHR)) are expecting children and young people to be research advisors and/or co-researchers, with statements of patient and public involvement being required in funding applications. For example, NIHR in their UK ten year plan for patient and public involvement and engagement published in 2015 commit to having "a population actively involved in research to improve health and wellbeing for themselves, their family and their communities" and the "public as partners in everything we do".⁴ Since 2012, a number of systematic or mapping reviews have been conducted on participatory research, however apart from reviews by Rouncefield-Swales¹ and Wilson et al.⁵ - which focus on health research - there has not been a synthesis involving different disciplines on participatory research in which children or young people collaborate with adult researchers and/or take a lead in particular aspects of the research. The interdisciplinary approach in this review will enable a refined examination of best practice in collaborative research with children and young people by drawing on social science and health understandings of interpersonal relationships and contexts, as well as diverse methodologies. This review co-produced with young people and adults experienced in participatory research, develops a broad definition of collaborative research with children and young people (i.e. children and/or young people explicitly involved in at least one stage of the research process beyond just generating data and involvement in dissemination or recruitment of participants). It draws on learning from different disciplines/approaches, including Youth Participatory Action Research (YPAR), public and patient engagement, citizen science, community-based peer research and some forms of collaborative research with children and young people.

As mentioned, involving children and young people as collaborators in the research process not only impacts on research design and quality but it can also produce creative and situated forms of 'learning in action' (6p359) as well as 'reflexive processes of social engagement' (6p359), which create new spaces for generating and using knowledge.⁶ However, achieving these potential benefits is known to be challenging as it can be hard to ensure that power is distributed, that children and young people's perspectives are valued, and that research is clearly linked into effective strategies for achieving personal and social change.⁷⁻¹⁰ There

continues to be a need for more guidance, particularly on collaborating with marginalised children and young people in ways that enables them to genuinely lead.¹¹

In addition to being left out of knowledge production in the ways that adults experience (due to the intersections of 'race', ethnicity, gender, class, sexuality and disability), children and young people who experience discrimination through intersecting social ontologies, social categories and social relations face further marginalisation in research.¹² The exclusion of children and young people is pervasive due to dominant conceptions of children and young people as an homogenised social category represented as incompetent, vulnerable, politically immature and needing the completion of education in order to deserve recognition as citizens and as competent researchers.¹³ Young people are often conceived of as apathetic or troublemakers, rather than recognising how young people are alienated by neo-liberal practices.¹⁴ The battle over what counts as evidence¹⁵ can also render children and young people's perspectives and sometimes their chosen means of expression, less valid than scientific orthodoxy.

Where children and young people are included in research, they are provided with information but tend to experience being 'researched on'. Their influence over the research priorities to investigate, approaches to analysis and guidance on the use of research findings is less evidenced. In 1999, Pole et al¹⁶ noted that, despite the turn towards participatory methods across multiple disciplines, children and young people do not have enough research capital to make them serious stakeholders in the research process. Brownlie⁷ repeated this, echoing the concern that "children and young people remain a long way from the emancipatory call of 'nothing about us, without us'"^(7p711). And still, a decade on, Lohmeyer⁸ repeats that "In theory, youth participatory methods are participant-led, and adults are involved in the process. However, there are social, historical, procedural and institutional barriers that make this ideal all but unachievable"^(8p44). This is despite the fact that some young people are "keen as f**k" to participate.⁸

Unless these barriers to collaborative research with children and young people are fully understood and strategies for overcoming the challenges are shared, research risks being perpetuated as yet another form of symbolic violence.^{17 18} That is, it will create conditions which perpetuate and normalise children and young people's subordinate position in processes of knowledge creation. Or, peer-led research may become a mechanism through which children and young people are exploited as lower paid or unpaid labour, to access young communities who are suspicious of mainstream health and social science research without allowing them power to identify what issues need investigating. There is therefore need for greater attention to the precise mechanisms, methods and reflexive stances which enable children and young people to lead research.¹⁸

Questions remain, however, about the kind of knowledge that is generated by collaborative research methods and attention to what we mean by concepts such as knowledge and epistemology. Young researchers cocreate methods, including digital methods¹⁹, photo-walks²⁰, map-making²¹ and storytelling²² which extend beyond traditional methods. Young researchers highlight that these methods are experienced positively by research participants^{23 24} and hence these co-creative approaches acknowledge shared responsibilities and skills in health and social research.²⁵ But these methods are not always valued by end users of research outputs, resulting in biases towards research that is not always congruent with children and young people's interests, concerns and contexts. Policy actors, funders and commissioners may need greater awareness of a diversity of approaches to rigour, quality and impact²⁶, and may need to extend

1
2
3 their understanding of health and social research to also recognise the validity that arises from
4 greater degrees of participation.²⁷ Evidence that can demonstrate how the knowledge from
5 collaborative research with children and young people can be valued by and acted on by
6 decision-makers may therefore provide further benefits.
7

8
9 What is needed is a synthesis of epistemologies and methodologies across a broad range of
10 different disciplines to establish key contexts for successful research by and with children and
11 young people. The current review addresses this gap by establishing precise mechanisms,
12 methods and reflexive stances which enable children and young people to lead and collaborate
13 as partners in research identifying best practice from existing evidence. The review will inform
14 both researchers and policy actors, funders and commissioners of the diversity of approaches
15 that may be appropriate to enable collaborative research with children and young people whilst
16 maintaining academic rigour and quality. Barriers and challenges will be highlighted to ensure
17 power imbalances are addressed and ways of working with marginalised groups will be
18 identified. The review will be useful to guide future collaborative research with children and
19 young people but will also identify key gaps in the evidence base where future work needs to
20 be conducted.
21
22

23 24 **Aim of the review**

25
26 To identify theoretical principles and practice modes and mechanisms of effective collaborative
27 research with children and young people in the field of health and social sciences, that are
28 generalisable as a basis for designing effective peer research projects, protocols and
29 establishing best practice.
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31

32 The mixed methods review will scope and synthesise existing knowledge about best practice
33 in conducting collaborative research with children and young people using the following
34 research questions co-created with young people and adults experienced in participatory
35 research:
36

- 37 1. What are the opportunities, barriers and tensions in collaborative research with children and
38 young people and how can these be understood and addressed?
39
- 40 2. What are the different modes and mechanisms of doing collaborative research with children
41 and young people? Which of these are valued, by whom, in which contexts and why?
42
- 43 3. How is success, impact and change documented, understood, negotiated and evaluated in
44 collaborative research with children and young people?
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48 Question 1 focusses specifically on issues identified by young people experienced in
49 participatory research as critical involving *cushions* (e.g. negotiated support with tasks, skills,
50 decision making and managing the emotional impact of conducting research), *credibility*,
51 *collaboration* and *change*. More detailed sub-questions have been devised to address these
52 highlighted issues:
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54

- 55 a) How do young and adult researchers ensure that young researchers have the *cushions*
56 they want throughout the research process?
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4 b) Which processes and structures ensure *collaborative* research is acceptable and
5 accessible to the diversity of children and young people (age, identity, experience of
6 discrimination, economic situations)?
7
8 c) How can we ensure that collaborative research with children and young people is
9 maximised in terms of strengthening claims to knowledge and *credibility*, conveying
10 convincing stories, linking to current opportunities and minimising risk of negative
11 attention?
12
13 d) Which processes and/or structures help ensure productive relationships between
14 stakeholders, allies, contexts and resources to support the use of evidence to make
15 *change* possible?
16

17 Ethics, safety, inclusion and power as themes relating to peer research will be considered across
18 all research questions. We will also report on the topics into which peer research has been
19 conducted and examine differences in modes, mechanisms and success across different topics.
20
21

22 **Methods and analysis**

23
24 This protocol is guided by the Preferred Items for Reporting of Systematic Reviews and Meta-
25 Analyses Protocols (PRISMA) checklist²⁸ (online supplemental appendix 1), Joanna Briggs
26 Institute (JBI) methodology for mixed-methods systematic reviews²⁹ and The Realist And
27 Meta-narrative Evidence Syntheses – Evolving Standards (RAMESES) publication standards
28 for realist syntheses and meta-narrative reviews.³⁰
29
30

31 **Study registration**

32
33 Based on the PRISMA guidelines²⁸, the protocol for this systematic review was registered on
34 the international database of prospectively registered systematic reviews in health and social
35 care, PROSPERO. Any important protocol amendments will be recorded in PROSPERO and
36 published with the results of the review.
37
38

39 Using the distinction of article types from Vaughn et al.³¹ selected articles will be grouped into
40 reviews, descriptive articles (those describing lessons learnt or a description of the programme)
41 and process articles (process or training of a peer model) and articles that focused on the peers
42 themselves and their experiences within a peer model/approach. The mixed methods review
43 will involve: 1) a systematic review of the review articles and a 2) realist synthesis of the
44 process, descriptive papers and those written by young co-researchers.
45
46

47 The systematic review of reviews will identify and establish the core models and methods used
48 in collaborative research with children and young people and the realist synthesis will offer a
49 more nuanced understanding of what works in collaborative research with children and young
50 people for whom, in what contexts and why. Findings will be triangulated and used to develop
51 a critical appraisal tool to assess collaborative research with children and young people.
52
53

54 **Eligibility criteria**

55
56 Studies and reviews will be selected according to the criteria set out below:
57
58

59 Types of studies
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1
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3 We will include systematic and scoping reviews, descriptive and process papers (using the
4 distinction made by Vaughn et al.³¹) relating to peer research, including also grey literature
5 reviews/reports. We will exclude papers that are exclusively empirical papers without
6 description of process or reflections, dissertations, editorials, opinion pieces, commentaries,
7 book or movie reviews, protocols, reports, case studies and erratum. We will only include
8 studies about collaborative research with children and young people. We will exclude studies
9 examining collaborative research in adult populations. Only studies written in English and only
10 those published from 2000 (due to the expedient growth in young people's involvement in
11 social research from 2000 onwards) will be included.
12
13

14 We will use a wide definition of collaborative research and include all reviews and
15 process/descriptive papers including a wide range of terms used to describe this type of
16 research (i.e. participatory research, community-led research, peer research informed social
17 action, community-based participatory research, peer led research, youth inquiry, co-
18 production, citizen science, youth participatory action research etc.).
19
20

21 Participants

22 We will include collaborative research with children and young people (aged 5-25 years) and
23 exclude collaborative research conducted with adults. Articles about research with primary
24 school aged children will be included to extrapolate potentially generalisable findings on peer
25 research to an older population of children and young people, but we will be mindful of
26 differences in developmental stages and needs.
27
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30 Outcomes

31 Theoretical principles, practice and mechanisms and findings in relation to power, inclusivity,
32 ethics, safeguarding, learning, methods, and impact.
33
34

35 We report on other important or critical factors and influencers of best practice in peer research
36 highlighted by selected papers.
37
38

39 Search strategy

40 We recruited a review steering group involving participants from Youth Endowment Fund,
41 study partners, appointed advisors and experienced young researchers from marginalised
42 groups, academics experienced in youth participation and relevant third sector professionals
43 and policy actors. Online discussions with this group (n = 18) were held in the form of a week-
44 long civic hackathon (³²; creative problem-solving sessions conducted once a day (1 ½ hours
45 long) for a full week in March 2021, also see Patient and Public Involvement Statement)
46 involving activities to enable:
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- 52 • Reflection and sharing of ideas about key concepts and challenges in peer research
- 53 • Reflection and definition of a proportionate systematic approach and relevant inclusion
54 criteria
- 55 • Agreement of research questions, inquiry themes and focus for the review
56
57

58 The findings from the online hackathon informed the focus of the research, search strategy,
59 inclusion and exclusion criteria and framework for synthesis.
60

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3
4 In addition, we conducted a priori scoping searches to identify key review papers in this specific
5 research area which also informed our search strategy.
6

7
8 We will use the Preferred Reporting Items for Systematic Review and Meta-Analysis checklist
9 (PRISMA³³) as a framework for the review.
10

11 We plan to conduct searches on eight bibliographic databases:

12
13 PsycINFO, Medline, CINAHL, Embase, SocINDEX, ASSIA: Applied Social Sciences
14 Index and Abstracts (Proquest), Social Care Online and SCOPUS
15
16

17 Handsearching will also be used, involving forward and backward chaining and examination
18 of references lists from reviews and key papers in this research area. We will also check
19 author's personal files for any key studies. In accordance with PRISMA guidelines³³, the
20 number of search results will be recorded at each stage of the study identification process. In
21 order to locate wider reviews on peer research that have been conducted we will include grey
22 literature reports, which will be obtained through Google searching using the key words (first
23 200 hits will be screened).
24
25

26 The following search terms have been developed following a priori scoping exercises and
27 online forum exercises with experienced young peer researchers and stakeholders:
28

29 (Child/ or Adolescent/ or child or children or kid or kids or girl* or boy* or adolescen*
30 or teen* or Youth* young people or young adult or young person or young men or
31 young women)
32
33

34 AND

35
36 Community-based participatory research/ or participatory research* or participatory
37 method* or participatory approach* or participatory design or participatory model* or
38 user led research or peer led research or peer research* or consumer led research or
39 action research or youth inquir* or co-produc* or coproduc* or co-research or
40 coresearch or co-creation or cocreation or co-design* or codesign* or co-develop* or
41 codevelop* or co-investigator* or coinvestigator* or citizen science or citizen scientist
42 or YPAR or advisory group* or advisory council or youth participation or young
43 involved or child led research* or peer model or research partner or social action)
44
45
46

47 The search strategy will be adapted to meet the truncation and Boolean operations of each
48 database as appropriate. The search strategy for each of the databases is presented (online
49 supplemental appendix 2).
50

51 **Study selection**

52
53 Papers identified from database searches will be downloaded to Endnote and any duplicates
54 removed. Screening by title and abstract will be conducted in Rayyan independently by one of
55 the authors, with at least 20% of the papers screened by another author. Decisions will be based
56 on the inclusion and exclusion criteria.
57
58
59
60

1
2
3 Once screening by title and abstract is complete, papers selected for full text screening will be
4 sourced and then examined by one author independently, with at least 20% of the papers
5 screened by another author. Reasons for exclusion will be noted at this stage.
6

7
8 Agreement at all stages will be made by consensus, and any disagreements regarding inclusion
9 will be discussed with a third reviewer. Inter-rater reliability will be recorded at each screening
10 stage (i.e. title, abstract and full text screening).
11

12 **Data extraction**

13
14
15 Following screening, data will be extracted from all selected texts using data extraction sheets
16 with a framework developed and co-created with the steering group. A separate data extraction
17 tool will be used for the review papers. As suggested by Daudt, van Mossel, and Scott³⁴ (2013)
18 at least 20% of data extracted will be charted by two authors independently using the data
19 extraction tool. Once sufficient agreement (> 80%) has been reached in the test phase, authors
20 will apply the tool to the remaining studies. Disagreements between the authors completing the
21 data extraction will be resolved through discussion, including the involvement of a third
22 reviewer where necessary. It is expected that data extraction will include key study
23 characteristics, participant characteristics, definitions of collaborative research, context
24 (geographical locations, service and community settings, and issues), models and mechanisms
25 (focussing specifically on research approaches and processes identified in hackathon activities:
26 relationships, attitudes, approaches, resources, distribution of leadership, timescales, and
27 change) and data relating to the co-created frameworks based on identified challenges and
28 tensions in peer research centred on *cushions*, *credibility*, *collaboration* and *change* (and other
29 aspects relating to outcome). Data extraction will include verbatim quotes from articles. We
30 will also chart any other important or critical factors and influencers of best practice in peer
31 research highlighted within selected papers.
32
33

34
35 During the data extraction stage, the research team will meet on a regular basis to discuss
36 progress, and to consider decisions regarding the relevance and adequacy of the data collection
37 tool. Those discussions will be documented along with any changes to the study protocol and
38 data extraction. Study authors will be contacted if additional information is required (e.g.
39 context related details of the study).
40
41

42 **Assessment of methodological quality**

43
44 Two authors will independently assess the research quality and bias of each of the included
45 articles involving studies of peer research using developed checklists based on existing
46 participation tools (e.g. Larkins et al.'s Participation Lattice³⁵; Shier's analytical tool³⁶) co-
47 created with the steering group and based on the results of activities in the hackathon. Using
48 these frameworks enables a critical appraisal of the participation of young people in the studies
49 rather than merely an assessment of research quality that is typically demonstrated by appraisal
50 tools to incorporate that the knowledge generated by collaborative research and how it is
51 reported does not always meet conventional standards of research quality. Discrepancies
52 between the review authors will be resolved by discussion, consulting a third review author
53 where necessary.
54
55

56
57 Two authors will independently assess the research quality and bias of all the review articles
58 included using the AMSTAR 2 Appraisal Tool³⁷ for systematic reviews. This tool is a
59 necessary starting point for the review of reviews, to measure quality of protocol and reporting
60

1
2
3 of systematic reviews. Adaptations of this tool will be developed alongside RAMESES, if
4 needed, to enable incorporation of wider literature (i.e. grey literature reports, realist reviews).
5 Inter-rater reliability will be reported and any discrepancies between authors will be resolved
6 through discussion or where necessary a third author will be consulted.
7
8

9 **Data synthesis**

10
11 Data extracted will be collated, summarised and synthesised narratively. Data will be presented
12 as tables, charts and/or visual maps in an aggregate rather than individual basis, to provide an
13 overview of the research field, summarise findings, identify gaps in the literature and make
14 recommendations for future research. Data analysis will be conducted in two phases: 1)
15 narrative synthesis of theoretical principles (i.e. definitions of peer research) and
16 mechanisms/methods used and 2) analysis of findings around contexts and the co-produced
17 thematic framework *cushions*, *credibility*, *collaboration* and *change* and 3) content and
18 thematic analysis using a co-created realist framework. We will explore youth characteristics
19 and contextual factors that influence what works for collaborative research with children and
20 young people. The realist review will aim to provide a theory outlining the contexts and
21 mechanisms and particular young people where collaborative research enables participation
22 and influence, placing specific emphasis on typically marginalised youth. The findings across
23 the different reviews will be collated into an accessible report focussing on identifying best
24 practice for collaborative research with children and young people.
25
26
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28

29 **Patient and public involvement**

30
31 The public were involved from the very start of developing the protocol. Young researchers
32 and non-academic third sector professionals (service providers and funders) took part in a series
33 of online discussions with academics. This was framed as a civic hackathon³², that is a series
34 of online events held in quick succession, with the aim of identifying what is currently
35 understood by the term peer research by and with children and young people, to explore the
36 challenges and potential of these approaches and to create a set of questions to guide the review.
37 Four online events were conducted, of around 90 minutes each, to frame the review. The events
38 were facilitated by senior academics experienced in participatory research with young people.
39 We used visual aids and online scribing to elicit the perspectives of young people and adults
40 experienced in participatory research and then guest academics were asked to respond to this.
41 At the end of every meeting we created a 3 minute summary of key discussion points and
42 perspectives and shared this, along with the visual and text notes of the meeting, to support the
43 participation of those who could not attend on specific days. Contributors to these non-
44 synchronous discussions tended to be academics. At the start of every meeting we reviewed
45 the story of our discussions so far, and summarised content that had been provided in between
46 meetings. At the end of the third meeting, ideas generated to date were used to draft initial
47 questions for the review. These were amended and finalised at the fourth meeting.
48
49
50
51

52 Whilst the review has been underway a further two online events have been held to discuss
53 emerging findings and potential outputs and a further four events are planned to enable young
54 researchers to contribute to at least one accessible output (an audio podcast has been planned)
55 and all academic articles. Young people have decided that the podcast will be shared on an
56 open access platform codesigned by young researchers for young researchers. All participants
57 in these activities either contributed as part of paid roles or received a thank you in the form of
58 vouchers.
59
60

Ethics and dissemination

Ethical approval and consent to participate are not required for the proposed systematic review as no primary data will be collected. Collaborative work with the experienced young researchers was conducted as part of an ongoing university research collaboration network. Young people receive information about the network and each activity. They, and their parents if under 16, provide signed consent to join the network and verbal consent to participate in any given activity. The findings of the mixed methods review will be written up as a report which will directly inform peer research training for the Peer Research and Social Action Network, funded by the Youth Endowment Fund together with the #iwill Fund and the Co-op Foundation. The Peer Research and Social Action Network will support young people affected by violence to become Peer Researchers and Changemakers. We will also explore opportunities with youth peer researchers to co-create accessible outputs to be disseminated through peer research networks. We expect that the findings will be written up in peer reviewed academic journals as a systematic review of reviews, realist synthesis reviews of papers about processes of peer research, and intergenerational reflections on the review process.

Contributors

CL is the guarantor. RN and CL drafted the manuscript. All authors contributed to the development of the selection criteria, the risk of bias assessment strategy and data extraction criteria. RN, CL and CH developed the search strategy. CL, LR, DS, NF, NM and AR provided expertise on peer research with children and young people. RN and LR provided expertise on systematic review methodology. All authors read, provided feedback and approved the final manuscript.

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Competing interests

None declared.

Data availability statement

Datasets (i.e. data extraction charts and analyses) will be available from the University of Central Lancashire's online repository (CLOK).

Acknowledgments

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PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol*

Section and topic	Item No	Checklist item	Section
ADMINISTRATIVE INFORMATION			
Title:			
Identification	1a	Identify the report as a protocol of a systematic review	Title, Method
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	n/a
Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number	Method: study registration
Authors:			
Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author	Title page
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	Authors contributions
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	n/a
Support:			
Sources	5a	Indicate sources of financial or other support for the review	Funding statement
Sponsor	5b	Provide name for the review funder and/or sponsor	Funding statement
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	Funding statement
INTRODUCTION			
Rationale	6	Describe the rationale for the review in the context of what is already known	Introduction
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	Aims of the review
METHODS			
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	Method
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage	Search strategy
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	Supplementary info

Study records:			
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	Method
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)	Method
Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	Method: data extraction
Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications	Method: data extraction
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	Method: data extraction
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	Assessment of methodological quality
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised	Method: data synthesis
	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 (such as I^2 , Kendall's τ)	n/a
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)	n/a
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	Method: data synthesis
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)	Method: data synthesis
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)	Method: data synthesis Assessment of methodological quality

*** It is strongly recommended that this checklist be read in conjunction with the PRISMA-P Explanation and Elaboration (cite when available) for important clarification on the items. Amendments to a review protocol should be tracked and dated. The copyright for PRISMA-P (including checklist) is held by the PRISMA-P Group and is distributed under a Creative Commons Attribution Licence 4.0.**

From: Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart L, PRISMA-P Group. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. BMJ. 2015 Jan 2;349(jan02 1):g7647.

Full Search strategies for each database

Medline

Search Number	Query
1	Child/
2	Adolescent/
3	(child or children or kid or kids or girl* or boy*).tw.
4	(adolescen* or teen* or youth\$1).tw.
5	(young adult* or young person or young people or young women or young men).tw.
6	or/1-5
7	Community-Based Participatory Research/
8	(participatory adj (research* or method* or approach* or design* or model*)).ti,ab,kw,kf.
9	(user led research or peer led research or child led research or youth led research or peer model* or peer research* or consumer led research or action research or social action or youth inquir*).ti,ab,kw,kf.
10	(co-produc* or coproduc* or co-research* or coresearch* or co-creation or cocreation or co-design* or codesign* or co-develop* or codevelop* or co-investigator* or coinvestigator*).ti,ab,kw,kf.
11	(citizen science or citizen scientist*).ti,ab,kw,kf.
12	(YPAR or ((youth or young or patient) adj2 (advisory group* or advisory council*))).ti,ab,kw,kf.
13	(youth adj2 (involvement or participation)).tw.
14	(research adj2 partner*).tw.
15	or/7-14
16	6 and 15
17	limit 16 to (english language and yr="2000 -Current")

Embase

Search Number	Query
1	child/
2	adolescent/
3	(child or children or kid or kids or girl* or boy*).tw.
4	(adolescen* or teen* or youth\$1).tw.
5	(young adult* or young person or young people or young women or young men).tw.
6	or/1-5
7	participatory research/
8	(participatory adj (research* or method* or approach* or design* or model*)).ti,ab,kw.
9	(user led research or peer led research or child led research or youth led research or peer model* or peer research* or consumer led research or action research or social action or youth inquir*).ti,ab,kw.
10	(co-produc* or coproduc* or co-research* or coresearch* or co-creation or cocreation or co-design* or codesign* or co-develop* or codevelop* or co-investigator* or coinvestigator*).ti,ab,kw.
11	(citizen science or citizen scientist*).ti,ab,kw.
12	(YPAR or ((youth or young or patient) adj2 (advisory group* or advisory council*))).ti,ab,kw.
13	(youth adj2 (involvement or participation)).tw.
14	(research adj2 partner*).tw.
15	or/7-14
16	6 and 15
17	limit 16 to (english language and yr="2000 -Current")

CINAHL

Search Number	Query
S1	(MH "Child")
S2	(MH "Adolescence")
S3	child or children or kid or kids or girl* or boy*
S4	adolescen* or teen* or youth*
S5	"young adult*" or "young person" or "young people" or "young women" or "young men"
S6	S1 OR S2 OR S3 OR S4 OR S5
S7	participatory N1 (research* or method* or approach* or design* or model*)
S8	"user led research" or "peer led research" or "child led research" or "youth led research" or "peer model*" or "peer research*" or "consumer led research" or "action research" or "social action" or "youth inquir**"
S9	"co-produc**" or coproduc* or "co-research*" or coresearch* or "co-creation" or cocreation or "co-design*" or codesign* or "co-develop*" or codevelop* or "co-investigator*" or coinvestigator*
S10	"citizen science" or "citizen scientist**"
S11	YPAR
S12	(youth or young or patient) N2 (advisory group* or advisory council*)
S13	youth N2 (involvement or participation)
S14	research N2 partner*
S15	S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14
S16	S6 AND S15
S17	Published Date: 20000101-; English Language

SocINDEX

Search Number	Query
S1	DE "CHILDREN" OR DE "ADOLESCENCE"
S2	child or children or kid or kids or girl* or boy*
S3	adolescen* or teen* or youth*
S4	"young adult*" or "young person" or "young people" or "young women" or "young men"
S5	S1 OR S2 OR S3 OR S4
S6	DE "COMMUNITY-based participatory research"
S7	participatory N1 (research* or method* or approach* or design* or model*)
S8	"user led research" or "peer led research" or "child led research" or "youth led research" or "peer model*" or "peer research*" or "consumer led research" or "action research" or "social action" or "youth inquir**"
S9	"co-produc**" or coproduc* or "co-research*" or coresearch* or "co-creation" or cocreation or "co-design*" or codesign* or "co-develop*" or codevelop* or "co-investigator*" or coinvestigator*
S10	"citizen science" or "citizen scientist**"
S11	YPAR
S12	(youth or young or patient) N2 ("advisory group*" or "advisory council**")
S13	youth N2 (involvement or participation)
S14	research N2 partner*
S15	S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14
S16	S5 AND S15
S17	Date of Publication: 20000101-

PyscINFO

Search Number	Query
S1	child or children or kid or kids or girl* or boy*
S2	adolescen* or teen* or youth*
S3	"young adult*" or "young person" or "young people" or "young women" or "young men"
S4	S1 OR S2 OR S3
S5	participatory N1 (research* or method* or approach* or design* or model*)
S6	"user led research" or "peer led research" or "child led research" or "youth led research" or "peer model*" or "peer research*" or "consumer led research" or "action research" or "social action" or "youth inquir*"
S7	"co-produc*" or coproduc* or "co-research*" or coresearch* or "co-creation" or cocreation or "co-design*" or codesign* or "co-develop*" or codevelop* or "co-investigator*" or coinvestigator*
S8	"citizen science" or "citizen scientist*"
S9	YPAR
S10	(youth or young or patient) N2 ("advisory group*" or "advisory council*")
S11	youth N2 (involvement or participation)
S12	research N2 partner*
S13	S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12
S14	S4 AND S13
S15	Limiters - Publication Year: 2000-; English

ASSIA

Query
(TI(child or children or kid or kids or girl* or boy* or adolescen* or teen* or youth* or "young adult*" or "young person" or "young people" or "young women" or "young men") or AB(child or children or kid or kids or girl* or boy* or adolescen* or teen* or youth* or "young adult*" or "young person" or "young people" or "young women" or "young men")) AND ((TI("participatory research*" or "participatory method*" or "participatory approach*" or "participatory design*" or "participatory model*" or "user led research" or "peer led research" or "child led research" or "youth led research" or "peer model*" or "peer research*" or "consumer led research" or "action research" or "social action" or "youth inquir*" or co-produc* or coproduc* or co-research* or coresearch* or co-creation or cocreation or co-design* or codesign* or co-develop* or codevelop* or co-investigator* or coinvestigator* or "citizen science" or "citizen scientist*" or YPAR) OR AB("participatory research*" or "participatory method*" or "participatory approach*" or "participatory design*" or "participatory model*" or "user led research" or "peer led research" or "child led research" or "youth led research" or "peer model*" or "peer research*" or "consumer led research" or "action research" or "social action" or "youth inquir*" or co-produc* or coproduc* or co-research* or coresearch* or co-creation or cocreation or co-design* or codesign* or co-develop* or codevelop* or co-investigator* or coinvestigator* or "citizen science" or "citizen scientist*" or YPAR)) OR (TI((youth or young or patient) NEAR/2 ("advisory group*" or "advisory council*")) OR AB((youth or young or patient) NEAR/2 ("advisory group*" or "advisory council*"))) OR (TI(youth NEAR/2 (involvement or participation)) OR AB(youth NEAR/2 (involvement or participation))) OR (TI(research NEAR/2 partner*) OR AB(research NEAR/2 partner*))

Scopus

Query

(TITLE-ABS-KEY (child OR children OR kid OR kids OR girl* OR boy* OR adolescen* OR teen* OR youth* OR "young adult*" OR "young person" OR "young people" OR "young women" OR "young men")) AND (TITLE-ABS-KEY (("participatory research*" OR "participatory method*" OR "participatory approach*" OR "participatory design*" OR "participatory model*" OR "user led research" OR "peer led research" OR "child led research" OR "youth led research" OR "peer model*" OR "peer research*" OR "consumer led research" OR "action research" OR "social action" OR "youth inquir*" OR "co-produc*" OR coproduc* OR "co-research*" OR coresearch* OR "co-creation" OR cocreation OR "co-design*" OR codesign* OR "co-develop*" OR codevelop* OR "co-investigator*" OR coinvestigator* OR "citizen science" OR "citizen scientist*" OR ypar) OR ((youth OR young OR patient) W/2 ("advisory group*" OR "advisory council*")) OR (youth W/2 (involvement OR participation)) OR (research W/2 partner*))) AND (LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009) OR LIMIT-TO (PUBYEAR , 2008) OR LIMIT-TO (PUBYEAR , 2007) OR LIMIT-TO (PUBYEAR , 2006) OR LIMIT-TO (PUBYEAR , 2005) OR LIMIT-TO (PUBYEAR , 2004) OR LIMIT-TO (PUBYEAR , 2003) OR LIMIT-TO (PUBYEAR , 2002) OR LIMIT-TO (PUBYEAR , 2001) OR LIMIT-TO (PUBYEAR , 2000)) AND (LIMIT-TO (LANGUAGE , "English")))

Social Care Online

Query

(TITLE-ABS-KEY (child OR children OR kid OR kids OR girl* OR boy* OR adolescen* OR teen* OR youth* OR "young adult*" OR "young person" OR "young people" OR "young women" OR "young men")) AND (TITLE-ABS-KEY (("participatory research*" OR "participatory method*" OR "participatory approach*" OR "participatory design*" OR "participatory model*" OR "user led research" OR "peer led research" OR "child led research" OR "youth led research" OR "peer model*" OR "peer research*" OR "consumer led research" OR "action research" OR "social action" OR "youth inquir*" OR "co-produc*" OR coproduc* OR "co-research*" OR coresearch* OR "co-creation" OR cocreation OR "co-design*" OR codesign* OR "co-develop*" OR codevelop* OR "co-investigator*" OR coinvestigator* OR "citizen science" OR "citizen scientist*" OR ypar) OR ((youth OR young OR patient) W/2 ("advisory group*" OR "advisory council*")) OR (youth W/2 (involvement OR participation)) OR (research W/2 partner*))) AND (LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009) OR LIMIT-TO (PUBYEAR , 2008) OR LIMIT-TO (PUBYEAR , 2007) OR LIMIT-TO (PUBYEAR , 2006) OR LIMIT-TO (PUBYEAR , 2005) OR LIMIT-TO (PUBYEAR , 2004) OR LIMIT-TO (PUBYEAR , 2003) OR LIMIT-TO (PUBYEAR , 2002) OR LIMIT-TO (PUBYEAR , 2001) OR LIMIT-TO (PUBYEAR , 2000)) AND (LIMIT-TO (LANGUAGE , "English")))