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

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Manuscripts

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3 1 **Involving adolescents in the design, implementation, evaluation, and dissemination of**
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6 2 **health research: an umbrella review protocol**
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14 Abstract

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

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

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

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3 37 **Umbrella review registration:** PROSPERO [CRD42021287467](https://www.crd.york.ac.uk/PROSPERO/record/CRD42021287467).

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5 38 **Strengths and limitations of this study**

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7
8 39 • This umbrella review consolidates evidence from a highly varied range of reviews on youth
9
10 40 involvement in health research, using a rigorous methodology and a comprehensive search
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12 41 strategy.
- 13
14
15 42 • This umbrella review will be conducted with active involvement from adolescents
16
17 43 throughout to improve the relevance, quality, and dissemination of the findings.
- 18
19 44 • Only reviews published in English will be included.
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25 46 **Keywords:** Youth involvement, Participatory action research, Public and Patient Involvement
26
27 47 (PPI), Health Research, Adolescent health.

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48 **Introduction**

49 Adolescents aged 10–24 years comprise 24% of the world's population (1). In the past two decades,
50 there has been a global shift in attention towards the promotion of adolescent health (2, 3). The
51 recent prioritization of adolescent health in global strategies (4, 5) is underpinned by a number of
52 factors. First, adolescents experience a considerable proportion of the global population's disease
53 burden, attributed to different communicable and non-communicable diseases and injuries (6, 7).
54 Around 168 million Disability-Adjusted Life Years (DALYs) are lost to adolescents' mental health
55 and physical health difficulties (6, 7). Second, establishing healthy behavioral patterns and
56 minimizing exposure to risk factors among adolescents is a strong determinant for future health
57 trajectories and can also improve the health of the next generation (3, 6). Third, the substantial
58 improvements in maternal and child health outcomes, which have been achieved in recent decades
59 through considerable global efforts, are at risk without adequate investments in adolescent health
60 (3, 6, 8, 9). Lastly, improvement in adolescent health outcomes promotes their productivity,
61 academic success, and future financial stability, and reduces the direct and indirect costs associated
62 with disease burden, resulting in societal and economic benefits (3, 6, 10-13). For these reasons,
63 adolescence is now widely considered a critical period in which to invest (3, 5, 9, 14), as reflected
64 in the increase in development assistance for adolescent health, from 109.7 million dollars in 2003
65 to 528.5 million dollars in 2015 (15).

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

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3 71 policy. Meaningful involvement of youth in health research is defined as "research that is done
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5 72 'with' or 'by'" young people, "not 'to', 'about' or 'for' them" (18, 19). Adolescents can be engaged
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7
8 73 to define and prioritize research questions, design the research process, ensure the appropriateness
9
10 74 of the research methodology for the young population, collect and analyze data, and disseminate
11
12 75 the research findings (17, 19-24). There are several frameworks to describe the involvement of
13
14 76 children and adolescents in research and health services. These include Hart's ladder of young
15
16 77 people's participation framework(25), Shier's pathways to participation framework (26), Treseder's
17
18 78 non-linear model of participation (27), Wong's TYPE Pyramid framework (28), Arunkumar's rope
19
20 79 ladder model (29), and the five-dimensional framework for young people's involvement in health
21
22 80 research (19). The frameworks most commonly used to describe and evaluate youth involvement
23
24 81 are those proposed by Roger Hart(25) and Harry Shier (26).

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29 82 In recent years, there has been an increasing emphasis on the meaningful involvement of
30
31 83 adolescents in health research, using participatory approaches (17, 23, 30-35). Three driving
32
33 84 factors explain the context of this change around the involvement of adolescents in health research
34
35 85 and service delivery(33). The first one is "consumer movement" (36), also equated with the term
36
37 86 "user involvement", emerging in the 1970s, that focuses on the integration of patients' views to
38
39 87 ensure responsive and acceptable health services (33, 37). This approach has assumed a central
40
41 88 position in NHS health policy for adults since the late nineties (38-40) and now encompasses the
42
43 89 involvement of adolescents in the design and delivery of health services and research (22, 33, 41).
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48 90 Second, Article 12 of the UN Convention on the Rights of the Child (16) emphasized that children
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50 91 and adolescents have a right to contribute to decisions regarding all matters relevant to young
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52 92 people and that their views must be taken into account. Almost all countries have now ratified this
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54 93 convention to achieve health equity by sharing power over decisions about adolescents (6, 42).
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3 94 This has led to a change in the perception of adolescents as social actors rather than passive
4
5 95 recipients of care and services designed and delivered by adult professionals (33, 34). This has
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8 96 also resulted in an unprecedented demand for the representation of adolescents in health-related
9
10 97 decision-making, with multiple health and funding organizations strongly advocating for the
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12 98 meaningful involvement of adolescents in health research to achieve the 2030 agenda for
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15 99 Sustainable Development (3, 17, 19, 43-45).

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18 100 Third, preliminary evidence on the impact of adolescents' contribution in health research highlights
19
20 101 multiple benefits of youth involvement from an operational, developmental, and societal
21
22 102 perspective (3, 6, 17, 19, 22, 33, 46, 47), further strengthening the cause for youth involvement.
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24
25 103 From an operational perspective, the involvement of adolescents improves research in several
26
27 104 ways: i) it ensures that the research questions reflect the needs and preferences of adolescents (17,
28
29 105 19, 21, 48), ii) enhances the recruitment and retention rates of participants (19, 49-53), iii)
30
31 106 improves data collection (19, 21, 54-58), iv) improves data analysis by bringing unique insight of
32
33
34 107 adolescents in translating the responses (19, 59, 60), and v) facilitates broader and more effective
35
36 108 dissemination of the findings (6, 19, 56, 61). Moreover, organizations that work with adolescents
37
38
39 109 report an overall change in the organization's culture to be more inclusive (62). From a
40
41 110 developmental perspective, several positive outcomes have been reported for adolescents who
42
43 111 contribute to research projects, including i) learning new research skills (19, 46, 63-68), ii)
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45 112 increased knowledge about health topics (19, 46, 50, 69-71), iii) better health outcomes (19, 46,
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47 113 70, 72), and iv) better academic or career outcomes (6, 19, 22, 63, 73-75). At the societal level, the
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50 114 involvement of adolescents has been linked with an increased awareness of different health issues
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52 115 in the community (17, 19, 62, 76-79).

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55 116 Despite growing recognition of the fundamental rights of adolescents to contribute to research and
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3 117 the potential benefits of involving them in research, Sellars et al. (2020) (17) found that less than
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5 118 1% of studies on child and adolescent health report involving adolescents as part of advisory
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8 119 groups. While involving young people in health research is on the rise, the overall number of
9
10 120 studies that involve youth is still low (19). This under-involvement of adolescents in health
11
12 121 research may be attributed to the challenges or barriers experienced by researchers and adolescents
13
14 122 contributing to research projects (17). These challenges include a lack of awareness of the evidence
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16 123 on youth involvement (19, 80), a need for extensive training to effectively engage youth in research
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18 124 (17, 19, 47, 56, 80-86), limited training resources and a lack of a comprehensive set of guidelines
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20 125 on engaging youth in health research (19, 47, 80, 87, 88), inadequate funding to support meaningful
21
22 126 youth involvement (82, 85, 89), difficulties in recruiting and retaining adolescents (85, 86, 90),
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24 127 complex ethical procedures such as additional consent and assent requirements, and compliance
25
26 128 with different safeguarding practices that vary for different contexts (48, 56, 91). To address some
27
28 129 of the highlighted challenges to meaningful youth involvement, we aim to develop a
29
30 130 comprehensive set of guidelines for involving youth in health research. This umbrella review will
31
32 131 inform the development of these guidelines by consolidating the review-level evidence on youth
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34 132 involvement in health research. There are numerous reviews on youth involvement in health
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36 133 research. However, these reviews focus on specific areas of health research (e.g., sexual and
37
38 134 reproductive health, mental health), certain types of youth involvement approaches (e.g., peer-
39
40 135 mediated interventions, participatory action research), specific locations (e.g., United States of
41
42 136 America, India), and are heterogenous in their methods (e.g., search different databases, use
43
44 137 different age groups etc.) and findings. Furthermore, there is little overlap in the studies that are
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46 138 included in these reviews, highlighting the need to bring together all available evidence on youth
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48 139 involvement in different areas of health research in different contexts and to translate these findings
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3 140 into recommendations. Given the broad scope of the research objectives and the heterogeneity in
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5 141 the extant literature, an umbrella review is a more suitable choice of review than a systematic
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8 142 review of primary studies (92).

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11 143 Therefore, we aim to conduct an umbrella review to i) summarize and synthesize findings from
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13 144 reviews on involving adolescents in health research, ii) consolidate the challenges experienced in
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15 145 youth involvement and the recommendations to mitigate these challenges, iii) identify the best
16
17 146 practices or recommendations on involving adolescents in health research, and iv) identify gaps
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20 147 and methodological weaknesses in the extant literature.

21 22 148 **Methods and analysis**

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24 149 This umbrella review will be conducted as per the Cochrane guidelines for overviews of reviews
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27 150 (93). However, some elements—types of reviews to be included and the appraisal method, in
28
29 151 particular—have been adapted (described below) to suit the objectives of the umbrella review. We
30
31 152 followed the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols
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33 153 (PRISMA-P) guidelines in reporting this protocol (Additional file 1). We will report findings in
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35
36 154 accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis
37
38 155 (PRISMA) statement (94) given that the PRISMA extension for overviews of reviews (Preferred
39
40 156 Reporting Items for Overviews of Reviews; PRIOR) is under development and is thus not available
41
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43 157 for this umbrella review (95). The umbrella review has been registered with the International
44
45 158 Prospective Register of Systematic Reviews (PROSPERO CRD42021287467). The PROSPERO
46
47 159 registration was updated to pre-register some changes to the methodology described below.

48 49 50 160 **Search strategy**

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53 161 The search strategy for this umbrella review includes keywords for; a) population (adolescents
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55 162 aged 10-24 years) (96), b) intervention or exposure (involvement of adolescents in health
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3 163 research), c) condition under study (health of adolescents), and d) review type (including
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5 164 narrative reviews, targeted reviews, rapid reviews, scoping reviews, literature reviews,
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8 165 qualitative reviews, integrated reviews, evidence maps, critical reviews, mixed methods reviews,
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10 166 overviews, state of the art reviews, practitioner reviews, systematic reviews, as well as meta-
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12 167 analyses) using Boolean syntax. Authors AW and KH developed the search strategy in
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14
15 168 consultation with a research librarian (GF) at Trinity College Dublin.

16
17 169 A commonly reported problem in studying youth involvement is the inconsistent use of
18
19
20 170 terminologies and a wide range of methodologies classified as youth involvement (19, 47). The
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22 171 search strategy is attached in the supplementary materials (Additional File 2).
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25 172 **Information sources**

26 27 173 **Electronic databases**

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30 174 We will search Cochrane Database of Systematic Reviews, Medical Literature Analysis and
31
32 175 Retrieval System Online (MEDLINE), Scopus, Embase, PsycINFO, PsycArticles, Cumulative
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34 176 Index to Nursing and Allied Health Literature (CINAHL), Epistemonikos, and Health Systems
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37 177 Evidence databases for potentially eligible reviews conducted up to 30th November 2021.
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40 178 **Grey literature search**

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43 179 The grey literature search involves several components. First, a simplified search strategy – based
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45 180 on different combinations of fewer key search terms – will be used to search Google Scholar for
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47 181 additional reviews. The Google Scholar search will be restricted to the first 10 pages. Second,
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50 182 we will identify the top 10 ranking pediatrics, perinatology, and child health journals using the
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52 183 Scimago Journal and Country Rank list for 2020 (17). A similar simplified version of the search
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54 184 strategy will be used to search these journals for additional reviews that could be potentially
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3 185 eligible for inclusion. Third, Web of Science and ProQuest will be searched to identify additional
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5 186 conference abstracts, theses, reports, and unpublished relevant reviews. The search strategy will
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8 187 be modified to suit the interface of these databases, as required. The search strategy for Web of
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10 188 Science is attached in the supplementary materials (Additional File 3). Fourth, we will search for
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12 189 relevant reviews registered on PROSPERO. Authors of potentially eligible reviews will be
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15 190 contacted to check whether the reviews are close to completion or have been completed. The
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17 191 authors will be requested to share the extracted data for inclusion in the umbrella review for
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19 192 complete or close to completion reviews. The number of contacts made and the number of
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21 193 authors who agreed to share the data will be recorded and reported. Fifth, websites of relevant
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23 194 organizations will also be searched for grey literature. This will involve compiling a list of
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25 195 organizations (including governmental, non-profit, and funding organizations) working on
26
27 196 adolescents' health. We will conduct a targeted search of up to 20 pages of Google, the Mental
28
29 197 Health Innovation Network database, and including organizations known to the authors. Then,
30
31 198 we will search for relevant documents by running a simplified search strategy, like the one used
32
33 199 for searching Google Scholar, on the website homepages of these organizations. The first ten
34
35 200 pages of the results will be searched. Websites without a search option will be hand-searched.
36
37 201 We will also search Google for youth health organizations in low- and middle-income countries
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39 202 and search the website of one organization (top google result) for each country. Names of all
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41 203 organizational websites searched, and the titles and URL links to eligible materials will be
42
43 204 extracted in the excel spreadsheet for grey literature, which will be posted on the review's [Open](#)
44
45 205 [Science Framework \(OSF\) page](#). Sixth, we will contact five to ten experts in youth involvement
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47 206 in health research. They will be regarded as an expert if, a) they oversee youth involvement in
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49 207 health research component at a funding organization (e.g., Wellcome Trust, Grand Challenges
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3 208 Canada) or youth health organization and/or, b) have conducted studies which involved
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5 209 adolescents as collaborators at different stages of the research process. We will include experts
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7 210 from high-, middle-, and low-income countries. After identifying potential experts to be
8
9 211 contacted, we will send them an email stating the aims of the umbrella review, eligibility criteria
10
11 212 for reviews, and a statement requesting that they share the references of any relevant materials
12
13 213 they might be familiar with. Seventh, reference lists of all eligible reviews will be reviewed to
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15 214 identify further relevant reviews. Finally, all the eligible reviews will be entered in the
16
17 215 connectedpapers software to identify similar papers. This comprehensive strategy aims to
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19 216 identify all published and unpublished reviews on this topic and get the broadest range of views
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21 217 possible for inclusion in the umbrella review.
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27 218 **Data management**

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30 219 All references from electronic databases will be exported to Covidence. We will record the search
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32 220 date, the number of results for each database and each combination of the search terms for grey
33
34 221 literature search. For the grey literature, titles and URL links to potentially relevant documents
35
36 222 will be entered in an excel spreadsheet for grey literature (97).
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39 223 **Eligibility Criteria**

40 224 **Study Design**

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44 225 Only review articles will be eligible for inclusion in this umbrella review. Although the Cochrane
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46 226 Overview of reviews guidelines recommend including systematic reviews and meta-analysis, we
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48 227 will include review articles of all types, including narrative reviews, targeted reviews, rapid
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50 228 reviews, scoping reviews, literature reviews, qualitative reviews, integrated reviews, evidence
51
52 229 maps, critical reviews, desk reviews, mixed methods reviews, overviews, state of the art reviews,
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54 230 practitioner reviews, systematic reviews, as well as meta-analyses (98). This adaptation to the
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3 231 guidelines is due to the qualitative nature of the outcomes of interest and to ensure the inclusion
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5 232 of a wide range of literature on youth involvement. This adaptation to the guidelines is common
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7
8 233 in umbrella reviews focusing on qualitative data and outcomes(99).
9

10 234 **Participants**

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14 235 We will only include reviews that discuss youth-specific results; the age range of participants in
15
16 236 studies included in the review can vary, but the target population of the review must include
17
18 237 adolescents. Adolescents are young people between the ages of 10 to 24 years as defined by
19
20 238 Sawyer et al. (96). All reviews focusing on children and adolescents irrespective of the age range
21
22
23 239 (as long as these include some studies for adolescents aged between 10 and 24 years) will be
24
25 240 included, but primary studies where the age range of the target population is below ten years or
26
27 241 above 24 years will be excluded. Reviews and studies where the age range is not mentioned, rather
28
29 242 the terms children and adolescents are listed will be included. No other restrictions will be applied
30
31 243 based on demographic characteristics or context.
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35 244 **Intervention**

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38 245 Reviews exploring youth involvement in studies that focus on the promotion of physical and
39
40 246 mental health or treatment of physical and mental health difficulties among adolescents will be
41
42 247 eligible. Youth involvement refers to a wide range of methods and strategies used to involve young
43
44
45 248 people in the design, conduct, analysis and dissemination of research on adolescent health.
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48 249 **Outcomes**

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51 250 Reviews including one or more of the following outcomes will be eligible for inclusion: i)
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53 251 strategies that have been used to involve adolescents in conducting health research, ii)
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55 252 recommendations for involving adolescents in health research (best practices), iii) barriers to
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253 meaningful youth involvement, iv) mitigation strategies to address these barriers and, v) evidence
254 gaps in youth involvement in health research.

255 **Other criteria**

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

261 **Selection of studies**

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

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

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

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

287 **Data extraction**

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

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

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3 297 aim of the review, definition of youth involvement used, search strategy, databases and
4
5 298 grey literature sources searched, search end date, method of synthesis, and tool used to
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8 299 appraise the risk of bias for the primary studies.
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11 300 **b)** Characteristics of primary studies include their eligibility criteria, the number of primary
12
13 301 studies included in the review, the study design of primary studies, and the risk of bias
14
15 302 results for the primary studies.
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18 303 **c)** Findings will consist of the use of different youth involvement strategies, level of youth
19
20 304 involvement, challenges, or barriers in the use of youth involvement strategies,
21
22 305 recommendations to address these barriers, best practices in youth involvement in health
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25 306 research, limitations of the review, and gaps identified in the literature.
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27

28 307 **Risk of bias assessment**

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31 308 A MeaSurement Tool to Assess systematic Reviews-2 (AMSTAR 2) (102) will be used to assess
32
33 309 the methodological quality of included systematic reviews. The risk of bias assessments conducted
34
35 310 for the primary studies in the included reviews will be narratively summarized. AW will conduct
36
37 311 the risk of bias assessment of all eligible systematic reviews, while a second reviewer will conduct
38
39 312 the risk of bias assessment for 10% of eligible systematic reviews. Any discrepancies or
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41 313 disagreements will be resolved through discussion among these two researchers and, if required,
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43 314 through discussion with a third researcher (KH).
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48 315 **Narrative synthesis**

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51 316 A narrative synthesis will be conducted to analyze the data. The first step will include
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53 317 familiarization with the extracted data through close reading, followed by coding the extracted
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55 318 data using deductive coding. Then, the codes will be structured under broader themes. Finally,
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3 319 these themes will be summarized in a descriptive and tabular form, centered around the research
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5 320 questions.

8 321 **Patient and Public Involvement**

10 322 Adolescents will be involved in the title and abstract screening, full-text screening, data extraction,
12 323 analysis, and dissemination phases of this umbrella review. These adolescents will be invited to
14 324 participate through local non-profit organizations and/or academic institutions. Specifically, an
16 325 adolescent co-researcher will be recruited to conduct title and abstract screening for 25% of the
18 326 articles and undertake full-text screening and data extraction for 10% of articles to ensure the
20 327 representation of youth in the decision-making process. Another youth co-researcher will
22 328 contribute to the data analysis by developing themes and writing up the narrative synthesis with
24 329 AW. To increase the relevance of the findings, 6-8 members of a youth advisory group will be
26 330 invited to share their interpretation of the results and reflections on the challenges and
28 331 recommendations highlighted in the literature. Additionally, they will contribute by reviewing the
30 332 outputs of this umbrella review and ensuring the language used is accessible and inclusive. We
32 333 will also facilitate the young co-researchers and advisors to present the findings to the scientific
34 334 community via video abstracts and to youth and lay audiences through dissemination methods
36 335 determined by the youth themselves to ensure more effective and wider dissemination of the
38 336 results.

46 337 **Discussion**

48 338 This review will bring together evidence on the most effective ways of involving adolescents in
50 339 health research, challenges experienced in this process, and mitigation strategies which have been
52 340 recommended to address or prevent these challenges. These findings will inform the development
54 341 of guidelines on involving adolescents in health research. The need for a comprehensive set of

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3 342 guidelines and resources on involving adolescents in health research has been highlighted by youth
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5 343 researchers (80) and studies (82, 103-106). These guidelines will facilitate researchers to
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7 344 collaborate with adolescents more effectively, leading to more meaningful involvement of
8
9 345 adolescents in research.

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12 346 This umbrella review has a few limitations. The search for eligible reviews will be restricted to the
13
14 347 English language. Additionally, while the search strategy incorporates a wide range of terms to
15
16 348 account for the variation in terminology around youth involvement, there is a possibility that
17
18 349 relevant reviews indexed using different terms will not be included. Moreover, umbrella reviews
19
20 350 are based on the information presented in the review articles and are therefore limited by the quality
21
22 351 of extracted data in the included reviews. Finally, there is a possibility of missing relevant data on
23
24 352 youth involvement in health research that has not previously been included in reviews. Any
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26 353 deviations to the submitted protocol will be documented as amendments to the PROSPERO
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28 354 registration.

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31 355 **Ethics and dissemination:** Only reviews will be included in this umbrella review; therefore, ethical
32
33 356 approval is not required. The findings of this umbrella review will be disseminated through peer-
34
35 357 reviewed publications, participatory workshops, and academic conferences.

36 358 **Supplementary Information**

37 359 Additional file 1. PRISMA-P Checklist.

38 360 Additional file 2. Search strategy for MEDLINE

39 361 Additional file 3. Search strategy for Web of Science

40 362 **Competing interests**

41 363 The authors declare that they have no competing interests.

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9
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11 369 **Authors' contributions**

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14 370 AW and KH conceptualized and wrote the protocol with valuable inputs from QK. DB, ML, PC
15
16 371 will contribute to the screening, data extraction and analysis of this review as young co-researchers.
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19 372 All authors have reviewed and approved the final manuscript.

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31 378 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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	1-2
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract	<input checked="" type="checkbox"/>	<input type="checkbox"/>	37
Authors					
Contact	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	<input checked="" type="checkbox"/>	<input type="checkbox"/>	6-12
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Support					
Sources	5a	Indicate sources of financial or other support for the review	<input checked="" type="checkbox"/>	<input type="checkbox"/>	363-367 372-377
Sponsor	5b	Provide name for the review funder and/or sponsor	<input checked="" type="checkbox"/>	<input type="checkbox"/>	363-367
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	307-314
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
	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)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	

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

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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:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2022-069695.R1
Article Type:	Protocol
Date Submitted by the Author:	27-Mar-2023
Complete List of Authors:	Warritch, 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

SCHOLARONE™
Manuscripts

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3 **1 Involving adolescents in the design, implementation, evaluation, and dissemination of**
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5 **2 health research: an umbrella review protocol**
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15 **6** Azza Warraitch*^{1,2}, Delali Bruce^{1,3}, Maria Lee^{1,2}, Paul Curran², Qusai Khraisha^{1,2}, Kristin
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14 Abstract

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

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

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

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3 37 **Umbrella review registration:** PROSPERO [CRD42021287467](https://www.crd.york.ac.uk/PROSPERO/record/CRD42021287467).

4
5 38 **Strengths and limitations of this study**

- 6
7
8 39 • This umbrella review consolidates evidence from a highly varied range of reviews on youth
9 involvement in health research, using a rigorous methodology and a comprehensive search
10 40 strategy.
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12 41
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14 42 • This umbrella review will be conducted with active involvement from adolescents
15 throughout to improve the relevance, quality, and dissemination of the findings.
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17 43
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19 44 • Only reviews published in English will be included.
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25 46 **Keywords:** Youth involvement, Participatory action research, Public and Patient Involvement
26 (PPI), Health Research, Adolescent health.
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48 **Introduction**

49 Adolescents aged 10–24 years comprise 24% of the world's population (1). In the past two decades,
50 there has been a global shift in attention towards the promotion of adolescent health (2, 3). The
51 recent prioritization of adolescent health in global strategies (4, 5) is underpinned by a number of
52 factors. First, adolescents experience a considerable proportion of the global population's disease
53 burden, attributed to different communicable and non-communicable diseases and injuries (6, 7).
54 Around 168 million Disability-Adjusted Life Years (DALYs) are lost to adolescents' mental health
55 and physical health difficulties (6, 7). Second, establishing healthy behavioral patterns and
56 minimizing exposure to risk factors among adolescents is a strong determinant for future health
57 trajectories and can also improve the health of the next generation (3, 6). Third, the substantial
58 improvements in maternal and child health outcomes, which have been achieved in recent decades
59 through considerable global efforts, are at risk without adequate investments in adolescent health
60 (3, 6, 8, 9). Lastly, improvement in adolescent health outcomes promotes their productivity,
61 academic success, and future financial stability, and reduces the direct and indirect costs associated
62 with disease burden, resulting in societal and economic benefits (3, 6, 10-13). For these reasons,
63 adolescence is now widely considered a critical period in which to invest (3, 5, 9, 14), as reflected
64 in the increase in development assistance for adolescent health, from 109.7 million dollars in 2003
65 to 528.5 million dollars in 2015 (15).

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

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3 71 policy. Meaningful involvement of youth in health research is defined as "research that is done
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5 72 'with' or 'by'" young people, "not 'to', 'about' or 'for' them" (18, 19). Adolescents can be engaged
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7
8 73 to define and prioritize research questions, design the research process, ensure the appropriateness
9
10 74 of the research methodology for the young population, collect and analyze data, and disseminate
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12 75 the research findings (17, 19-24). There are several frameworks to describe the involvement of
13
14 76 children and adolescents in research and health services. These include Hart's ladder of young
15
16 77 people's participation framework (25), Shier's pathways to participation framework (26),
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18 78 Treseder's non-linear model of participation (27), Wong's TYPE Pyramid framework (28),
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20 79 Arunkumar's rope ladder model (29), and the five-dimensional framework for young people's
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22 80 involvement in health research (19). The frameworks most commonly used to describe and
23
24 81 evaluate youth involvement are those proposed by Hart (25) and Shier (26).

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29 82 Hart's ladder of young people's participation builds on Arnstein's ladder of citizen participation for
30
31 83 adults (30). This framework refers to eight steps in the ladder of participation: manipulation,
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33 84 decoration, tokenism, assigned but informed, consulted and informed, adult-initiated shared
34
35 85 decisions with children, child-initiated and directed, and child-initiated shared decisions with
36
37 86 adults. Meaningful engagement begins at the fourth step of the ladder and ends with shared
38
39 87 decision-making at the highest step (25). Shier proposed an alternative framework that focuses on
40
41 88 elements of meaningful involvement. Shier's 'pathways to participation' model proposes five levels
42
43 89 of involvement, where on the first level young people are listened to, on the second level they are
44
45 90 supported to express their views, on the third level their views are taken into account, on the fourth
46
47 91 level they are involved in decision-making processes and on the fifth level they share power and
48
49 92 responsibility for decision making with the researchers (26). The relative simplicity of this model
50
51 93 makes it one of the most widely used frameworks for youth involvement (19, 31).

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3 94 In recent years, there has been an increasing emphasis on the meaningful involvement of
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5 95 adolescents in health research, using participatory approaches (17, 23, 31-36). Three driving
6
7 96 factors explain the context of this change around the involvement of adolescents in health research
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9
10 97 and service delivery(31). The first one is "consumer movement" (37), also equated with the term
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12 98 "user involvement", emerging in the 1970s, that focuses on the integration of patients' views to
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15 99 ensure responsive and acceptable health services (31, 38). This approach has assumed a central
16
17 100 position in the National Health Service (NHS) health policy for adults since the late nineties (39-
18
19 101 41) and now encompasses the involvement of adolescents in the design and delivery of health
20
21 102 services and research (22, 31, 42).

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24 103 Second, Article 12 of the UN Convention on the Rights of the Child (16) emphasized that children
25
26 104 and adolescents have a right to contribute to decisions regarding all matters relevant to young
27
28 105 people and that their views must be taken into account. Almost all countries have now ratified this
29
30 106 convention to achieve health equity by sharing power over decisions about adolescents (6, 43).
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32
33 107 This has led to a change in the perception of adolescents as social actors rather than passive
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35 108 recipients of care and services designed and delivered by adult professionals (31, 35). This has
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37 109 also resulted in an unprecedented demand for the representation of adolescents in health-related
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39 110 decision-making, with multiple health and funding organizations strongly advocating for the
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41 111 meaningful involvement of adolescents in health research to achieve the 2030 agenda for
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43 112 Sustainable Development (3, 17, 19, 44-46).

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48 113 Third, preliminary evidence on the impact of adolescents' contribution in health research highlights
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50 114 multiple benefits of youth involvement from an operational, developmental, and societal
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52 115 perspective (3, 6, 17, 19, 22, 31, 47, 48), further strengthening the cause for youth involvement.
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55 116 From an operational perspective, the involvement of adolescents improves research in several
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3 117 ways: i) it ensures that the research questions reflect the needs and preferences of adolescents (17,
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5 118 19, 21, 49), ii) enhances the recruitment and retention rates of participants (19, 50-54), iii)
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7 119 improves data collection (19, 21, 55-59), iv) improves data analysis by bringing unique insight of
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9 120 adolescents in translating the responses (19, 60, 61), and v) facilitates broader and more effective
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11 121 dissemination of the findings (6, 19, 57, 62). Moreover, organizations that work with adolescents
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13 122 report an overall change in the organization's culture to be more inclusive (63). From a
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15 123 developmental perspective, several positive outcomes have been reported for adolescents who
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17 124 contribute to research projects, including i) learning new research skills (19, 47, 64-69), ii)
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19 125 increased knowledge about health topics (19, 47, 51, 70-72), iii) better health outcomes (19, 47,
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21 126 71, 73), and iv) better academic or career outcomes (6, 19, 22, 64, 74-76). At the societal level, the
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23 127 involvement of adolescents has been linked with an increased awareness of different health issues
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25 128 in the community (17, 19, 63, 77-80).

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31 129 Despite growing recognition of the fundamental rights of adolescents to contribute to research and
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33 130 the potential benefits of involving them in research, Sellars et al (17) found that less than 1% of
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35 131 studies on child and adolescent health report involving adolescents as part of advisory groups.
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37 132 While involving young people in health research is on the rise, the overall number of studies that
38
39 133 involve youth is still low (19). This under-involvement of adolescents in health research may be
40
41 134 attributed to the challenges or barriers experienced by researchers and adolescents contributing to
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43 135 research projects (17). These challenges include a lack of awareness of the evidence on youth
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45 136 involvement (19, 81), a need for extensive training to effectively engage youth in research (17, 19,
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47 137 48, 57, 81-87), limited training resources and a lack of a comprehensive set of guidelines on
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49 138 engaging youth in health research (19, 48, 81, 88, 89), inadequate funding to support meaningful
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51 139 youth involvement (83, 86, 90), difficulties in recruiting and retaining adolescents (86, 87, 91),
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3 140 complex ethical procedures such as additional consent and assent requirements, and compliance
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5 141 with different safeguarding practices that vary for different contexts (49, 57, 92). To address some
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7 142 of the highlighted challenges to meaningful youth involvement, we aim to develop a
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9 143 comprehensive set of guidelines for involving youth in health research. While there are several
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11 144 guidelines available on involvement of young people in health research, a recent review
12
13 145 highlighted that these guidelines are limited in their scope, contexts, and the content that they cover
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15 146 (19). For example, overlooked areas of youth involvement such as involvement in the early and
16
17 147 late stages of the research process, working with young people in LMICs, and working with those
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19 148 from disadvantaged groups, are some aspects that need to be emphasised in a set of comprehensive
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21 149 guidelines (81). While subject-specific guidelines, where they exist, may offer more targeted
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23 150 guidance on engaging young people in research on specific health issues, a comprehensive set of
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25 151 guidelines can be of use to a larger target audience of those working with youth in different types
26
27 152 of health areas. Furthermore, as most of the principles of youth engagement are transdisciplinary
28
29 153 (e.g., informed consent, power dynamics, inclusivity), an overall set of guidelines holds the
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31 154 potential to be useful and relevant to a wider audience working on a range of health research areas.
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33 155 This umbrella review will inform the development of these guidelines by consolidating the review-
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35 156 level evidence on youth involvement in health research. This umbrella review will be followed by
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37 157 a rapid review to consolidate the recommendations from the existing guidelines on youth
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39 158 engagement in health research. Further details on the guideline development process can be
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41 159 accessed on the OSF page. There are numerous reviews on youth involvement in health research.
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43 160 However, these reviews focus on specific areas of health research (e.g., sexual and reproductive
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45 161 health, mental health), certain types of youth involvement approaches (e.g., peer-mediated
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47 162 interventions, participatory action research), specific locations (e.g., United States of America,
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3 163 India), and are heterogenous in their methods (e.g., search different databases, use different age
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5 164 groups etc.) and findings. Furthermore, there is little overlap in the studies that are included in
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8 165 these reviews, highlighting the need to bring together all available evidence on youth involvement
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10 166 in different areas of health research in different contexts and to translate these findings into
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12 167 recommendations. Given the broad scope of the research objectives and the heterogeneity in the
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15 168 extant literature, an umbrella review is a more suitable choice of review than a systematic review
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17 169 of primary studies (93).

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20 170 Therefore, we aim to conduct an umbrella review to i) summarize and synthesize findings from
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22 171 reviews on involving adolescents in health research, ii) consolidate the challenges experienced in
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24 172 youth involvement and the recommendations to mitigate these challenges, iii) identify the best
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27 173 practices or recommendations on involving adolescents in health research, and iv) identify gaps
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29 174 and methodological weaknesses in the extant literature.

30 31 175 **Methods and analysis**

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34 176 This umbrella review will be conducted as per the Cochrane guidelines for overviews of reviews
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36 177 (94). However, some elements—types of reviews to be included and the appraisal method, in
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38 178 particular—have been adapted (described below) to suit the objectives of the umbrella review. We
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41 179 followed the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols
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43 180 (PRISMA-P) guidelines in reporting this protocol (Additional file 1). We will report findings in
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45 181 accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis
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47 182 (PRISMA) statement (95) given that the PRISMA extension for overviews of reviews (Preferred
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50 183 Reporting Items for Overviews of Reviews; PRIOR) is under development and is thus not available
51
52 184 for this umbrella review (96). The umbrella review has been registered with the International
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3 185 Prospective Register of Systematic Reviews (PROSPERO CRD42021287467). The PROSPERO
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5 186 registration was updated to pre-register some changes to the methodology described below.
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8 187 **Search strategy**

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10 188 The search strategy for this umbrella review includes keywords for; a) population (adolescents
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12 189 aged 10-24 years) (97), b) intervention or exposure (involvement of adolescents in health
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14 190 research), c) condition under study (health of adolescents), and d) review type (including
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16 191 narrative reviews, targeted reviews, rapid reviews, scoping reviews, literature reviews,
17
18 192 qualitative reviews, integrated reviews, evidence maps, critical reviews, mixed methods reviews,
19
20 193 overviews, state of the art reviews, practitioner reviews, systematic reviews, as well as meta-
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22 194 analyses) using Boolean syntax. Authors AW and KH developed the search strategy in
23
24 195 consultation with a research librarian (GF) at Trinity College Dublin.
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29 196 A commonly reported problem in studying youth involvement is the inconsistent use of
30
31 197 terminologies and a wide range of methodologies classified as youth involvement (19, 48). The
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33 198 search strategy is attached in the supplementary materials (Additional File 2).
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37 199 **Information sources**

38 39 200 **Electronic databases**

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42 201 We will search Cochrane Database of Systematic Reviews, Medical Literature Analysis and
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44 202 Retrieval System Online (MEDLINE), Scopus, Embase, PsycINFO, PsycArticles, Cumulative
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46 203 Index to Nursing and Allied Health Literature (CINAHL), Epistemonikos, and Health Systems
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48 204 Evidence databases for potentially eligible reviews conducted up to 30th November 2021.
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52 205 **Grey literature search**

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3 206 The grey literature search involves several components. First, a simplified search strategy – based
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5 207 on different combinations of fewer key search terms – will be used to search Google Scholar for
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7 208 additional reviews. The Google Scholar search will be restricted to the first 10 pages. Second,
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9 209 we will identify the top 10 ranking pediatrics, perinatology, and child health journals using the
10
11 210 Scimago Journal and Country Rank list for 2020 (17). A similar simplified version of the search
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13 211 strategy will be used to search these journals for additional reviews that could be potentially
14
15 212 eligible for inclusion. Third, Web of Science and ProQuest will be searched to identify additional
16
17 213 conference abstracts, theses, reports, and unpublished relevant reviews. The search strategy will
18
19 214 be modified to suit the interface of these databases, as required. The search strategy for Web of
20
21 215 Science is attached in the supplementary materials (Additional File 3). Fourth, we will search for
22
23 216 relevant reviews registered on PROSPERO. Authors of potentially eligible reviews will be
24
25 217 contacted to check whether the reviews are close to completion or have been completed. The
26
27 218 authors will be requested to share the extracted data for inclusion in the umbrella review for
28
29 219 complete or close to completion reviews. The number of contacts made and the number of
30
31 220 authors who agreed to share the data will be recorded and reported. Fifth, websites of relevant
32
33 221 organizations will also be searched for grey literature. This will involve compiling a list of
34
35 222 organizations (including governmental, non-profit, and funding organizations) working on
36
37 223 adolescents' health. We will conduct a targeted search of up to 20 pages of Google, the Mental
38
39 224 Health Innovation Network (MHIN) database, and including organisations known to the authors.
40
41 225 The mental health innovation network is a community of global mental health researchers, health
42
43 226 professionals, policymakers, and other relevant stakeholders. MHIN has a database of
44
45 227 organizations working to promote health in communities in low-, middle-, and high-income
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47 228 countries. The MHIN database interface has search options for organizations based on the target
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3 229 population that they work with and the countries. We will use the filter for age range to identify
4
5 230 the organizations that work with young people. After identifying the organizations, we will
6
7
8 231 search for relevant documents by running a simplified search strategy, like the one used for
9
10 232 searching Google Scholar, on the website homepages of these organizations. The first ten pages
11
12 233 of the results will be searched. Websites without a search option will be hand-searched. We will
13
14 234 also search Google for youth health organizations in low- and middle-income countries and
15
16 235 search the website of one organization (top google result) for each country. We will use World
17
18 236 Bank's classification of countries to define low- and middle-income countries and DAC list of
19
20 237 ODA recipients(98). We will only search the website of the organization that is the top google
21
22 238 result for each of the 137 low- and middle-income countries to ensure at least one organisation
23
24 239 from each country is included. Names of all organisational websites searched, and the titles and
25
26 240 URL links to eligible materials will be extracted in the excel spreadsheet for grey literature,
27
28 241 which will be posted on the review's [Open Science Framework \(OSF\) page](#). Sixth, we will
29
30 242 contact five to ten experts in youth involvement in health research. They will be regarded as an
31
32 243 expert if, a) they oversee youth involvement in health research component at a funding
33
34 244 organization (e.g., Wellcome Trust, Grand Challenges Canada) or youth health organization
35
36 245 and/or, b) have conducted studies which involved adolescents as collaborators at different stages
37
38 246 of the research process. We will include experts from high-, middle-, and low-income countries.
39
40 247 After identifying potential experts to be contacted, we will send them an email stating the aims
41
42 248 of the umbrella review, eligibility criteria for reviews, and a statement requesting that they share
43
44 249 the references of any relevant materials they might be familiar with. Seventh, reference lists of
45
46 250 all eligible reviews will be reviewed to identify further relevant reviews. Finally, all the eligible
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48 251 reviews will be entered in the connectedpapers software to identify similar papers. This
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3 252 comprehensive strategy aims to identify all published and unpublished reviews on this topic and
4
5 253 get the broadest range of views possible for inclusion in the umbrella review. The grey literature
6
7
8 254 search will be conducted by AW.
9

10 255 **Data management**

11
12
13
14 256 All references from electronic databases will be exported to Covidence. We will record the search
15
16 257 date, the number of results for each database and each combination of the search terms for grey
17
18 258 literature search. For the grey literature, titles and URL links to potentially relevant documents
19
20
21 259 will be entered in an excel spreadsheet for grey literature (99).
22

23 260 **Eligibility Criteria**

24 25 261 **Study Design**

26
27
28 262 Only review articles will be eligible for inclusion in this umbrella review. Although the Cochrane
29
30 263 Overview of reviews guidelines recommend including systematic reviews and meta-analysis, we
31
32 264 will include review articles of all types, including narrative reviews, targeted reviews, rapid
33
34 265 reviews, scoping reviews, literature reviews, qualitative reviews, integrated reviews, evidence
35
36 266 maps, critical reviews, desk reviews, mixed methods reviews, overviews, state of the art reviews,
37
38 267 practitioner reviews, systematic reviews, as well as meta-analyses (100). This adaptation to the
39
40 268 guidelines is due to the qualitative nature of the outcomes of interest and to ensure the inclusion
41
42 269 of a wide range of literature on youth involvement. This adaptation to the guidelines is common
43
44 270 in umbrella reviews focusing on qualitative data and outcomes (101).
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49 271 **Participants**

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51
52 272 We will only include reviews that discuss youth-specific results; the age range of participants in
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54 273 studies included in the review can vary, but the target population of the review must include
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3 274 adolescents. Adolescents are young people between the ages of 10 to 24 years as defined by
4
5 275 Sawyer et al. (97). All reviews focusing on children and adolescents irrespective of the age range
6
7 276 (as long as these include some studies for adolescents aged between 10 and 24 years) will be
8
9
10 277 included, but primary studies where the age range of the target population is below ten years or
11
12 278 above 24 years will be excluded. Reviews and studies where the age range is not mentioned, rather
13
14 279 the terms children and adolescents are listed will be included. No other restrictions will be applied
15
16 280 based on demographic characteristics or context. Reviews that are overlapping in terms of age
17
18 281 range will be included, however, overlap in the primary studies included in reviews will be
19
20 282 addressed using the procedure described below in study selection section.
21
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23

24 283 We are focusing on adolescents aged 10-24 for three reasons; i) this umbrella review aims to
25
26 284 inform the development of a set of comprehensive guidelines on involvement of adolescents aged
27
28 285 10-24 to address the gaps in the currently available guidelines on involvement of adolescents in
29
30 286 health research (19), ii) based on their developmental status, the methods used to engage children
31
32 287 might be different than the ones used to engage adolescents therefore the recommendations for
33
34 288 both age groups would vary, iii) logistical considerations including the additional time and
35
36 289 resources required to develop recommendations on engaging children younger than 10 years.
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41 290 **Intervention**

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44 291 Reviews exploring youth involvement in studies that focus on the promotion of physical and
45
46 292 mental health or treatment of physical and mental health difficulties among adolescents will be
47
48 293 eligible. We will include reviews focusing on overall youth engagement as long as these include
49
50 294 at least one study on youth involvement in health research in accordance with Cochrane guidelines
51
52 295 which advise that where a particular review's research objectives are broader than those of an
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3 296 umbrella review, the umbrella review should only include primary studies from that review that
4
5 297 meet the eligibility criteria for the umbrella review (94).
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8 298 Youth involvement in health research refers to a wide range of methods and strategies used to
9
10 299 involve young people in the design, conduct, analysis, and dissemination of research on adolescent
11
12 300 health. Their involvement can range from consultation where young people are asked for advice
13
14 301 and to share their views to inform decision-making (22), to collaboration which is characterised
15
16 302 by “active, on-going partnership with young people” (22) and youth led research which involves
17
18 303 “putting the locus of power, initiative and subsequent decision-making with young people” (22).
19
20 304 This review will focus on all three levels of youth involvement in addition to all approaches to
21
22 305 youth involvement.
23
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27 306 **Outcomes**

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29
30 307 Reviews including one or more of the following outcomes will be eligible for inclusion: i)
31
32 308 strategies that have been used to involve adolescents in conducting health research, ii)
33
34 309 recommendations for involving adolescents in health research (best practices), iii) barriers to
35
36 310 meaningful youth involvement, iv) mitigation strategies to address these barriers and, v) evidence
37
38 311 gaps in youth involvement in health research.
39
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41

42 312 **Other criteria**

43
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45 313 Only reviews published in the English language will be considered for inclusion. Reviews where
46
47 314 data extraction tables for the primary studies (applicable to systematic, rapid, and scoping reviews)
48
49 315 are inaccessible will be excluded. As per the Cochrane guidelines for overviews of reviews (94),
50
51 316 if a review’s research objectives and scope are broader than the current umbrella review, the subset
52
53 317 of primary studies meeting the review's eligibility criteria will be included in this umbrella review.
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318 **Selection of studies**

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

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

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

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3 341 that include a primary study. The overlap will be quantified by calculating the corrected covered
4
5 342 area measure (104) that indicates the degree of overlap. The citation matrix will help us ensure
6
7
8 343 that the results of primary studies included in multiple reviews are only included once (103, 104).
9
10 344 This citation matrix will be posted on the review's [OSF page](#).

13 345 **Data extraction**

14
15
16 346 Data from the included reviews will be extracted using a data extraction form designed in
17
18 347 Covidence. The data extraction form will be piloted by researchers extracting the data, using 1%
19
20 348 of eligible full-text articles. Inter-rater reliability between the researchers will be assessed using
21
22 349 the kappa statistic for the closed-ended fields of the data extraction form and risk of bias assessment.
23
24
25 350 For open-ended data extraction fields, AW will compare the data extracted by all team members
26
27 351 to assess whether a general agreement has been established on the data extraction process. Data on
28
29
30 352 results will be extracted only from the included reviews. Data will be extracted on:

31
32
33 353 **a)** Characteristics of eligible reviews including review title, names and contact details of study
34
35 354 authors, publication type (e.g., article, conference abstract, report, etc.), review type
36
37 355 (scoping, narrative, systematic, etc.), the age range of study population in the review, the
38
39 356 condition under study (e.g., physical health, mental health, or specific disease/disorder),
40
41 357 aim of the review, definition of youth involvement used, search strategy, databases and
42
43
44 358 grey literature sources searched, search end date, method of synthesis, and tool used to
45
46 359 appraise the risk of bias for the primary studies.

47
48
49 360 **b)** Characteristics of primary studies include their eligibility criteria, the number of primary
50
51 361 studies included in the review, the study design of primary studies, and the risk of bias
52
53
54 362 results for the primary studies.

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3 363 c) Findings will consist of the use of different youth involvement strategies, level of youth
4
5 364 involvement, challenges, or barriers in the use of youth involvement strategies,
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7
8 365 recommendations to address these barriers, best practices in youth involvement in health
9
10 366 research, limitations of the review, and gaps identified in the literature.
11
12

13 367 **Risk of bias assessment**

14
15
16 368 A MeaSurement Tool to Assess systematic Reviews-2 (AMSTAR 2) (105) will be used to assess
17
18 369 the methodological quality of included systematic reviews. The risk of bias assessments conducted
19
20 370 for the primary studies in the included reviews will be narratively summarized. AW will conduct
21
22 371 the risk of bias assessment of all eligible systematic reviews, while a second reviewer will conduct
23
24 372 the risk of bias assessment for 10% of eligible systematic reviews. Any discrepancies or
25
26 373 disagreements will be resolved through discussion among these two researchers and, if required,
27
28 374 through discussion with a third researcher (KH).
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33 375 **Narrative synthesis**

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35
36 376 A narrative synthesis will be conducted by AW and a youth co-researcher to analyse the data. The
37
38 377 first step will include familiarization with the extracted data through close reading, followed by
39
40 378 coding the extracted data using deductive coding. Then, the codes will be structured under broader
41
42 379 themes. Finally, these themes will be summarised in a descriptive and tabular form, centred around
43
44 380 the research aims and objectives. AW and a youth co-researcher will analyse a subset of the data
45
46 381 together until there is a general agreement on the coding and narrative building.
47
48
49

50 382 **Patient and Public Involvement**

51
52 383 Adolescents will be involved in the title and abstract screening, full-text screening, data extraction,
53
54 384 analysis, and dissemination phases of this umbrella review. These adolescents will be invited to
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3 385 participate through local non-profit organizations and/or academic institutions. Specifically, the
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5 386 youth co-researchers and co-authors DB, ML, and PC reviewed the final protocol for the umbrella
6
7 387 review and shared their input. An adolescent co-researcher will be recruited to conduct title and
8
9 388 abstract screening for 25% of the articles and undertake full-text screening and data extraction for
10
11 389 10% of articles to ensure representation of youth in decision-making processes. Another youth co-
12
13 390 researcher will contribute to the data analysis by working with AW to develop themes and write
14
15 391 up the narrative synthesis. To increase the relevance of the findings, we will seek input from 6-8
16
17 392 members of a youth advisory group in two participatory workshops. In the first workshop, young
18
19 393 people will be invited to share their interpretation of the results and reflections on the challenges
20
21 394 and recommendations highlighted in the literature. In the second workshop, they will contribute
22
23 395 by reviewing the outputs of this umbrella review and ensuring the language used is accessible and
24
25 396 inclusive. We will also facilitate the young co-researchers and advisors to present the findings to
26
27 397 the scientific community via video abstracts and to youth and lay audiences through dissemination
28
29 398 methods determined by the youth themselves to ensure more effective and wider dissemination of
30
31 399 the results. Youth co-researchers will also help us recruit youth advisors for the review. Previous
32
33 400 experience of research will not be a criterion for youth co-researchers to be engaged in this project.
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401 **Discussion**

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

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3 408 collaborate with adolescents more effectively, leading to more meaningful involvement of
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5 409 adolescents in research.
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8 410 This umbrella review has a few limitations. The search for eligible reviews will be restricted to the
9
10 411 English language. Additionally, while the search strategy incorporates a wide range of terms to
11
12 412 account for the variation in terminology around youth involvement, there is a possibility that
13
14 413 relevant reviews indexed using different terms will not be included. Moreover, umbrella reviews
15
16 414 are based on the information presented in the review articles and are therefore limited by the quality
17
18 415 of extracted data in the included reviews. There is also a possibility of missing relevant data on
19
20 416 youth involvement in health research that has not previously been included in reviews. This review
21
22 417 only focuses on involvement of adolescents aged 10-24 in health research therefore the findings
23
24 418 of the review will not be generalisable to children younger than 10 years. Given the focus on
25
26 419 adolescent involvement in health research, any relevant guidance on engaging young people based
27
28 420 on research in other disciplines and fields may be excluded. Any deviations to the submitted
29
30 421 protocol will be documented as amendments to the PROSPERO registration.
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36 422 **Ethics and dissemination:** Only reviews will be included in this umbrella review; therefore, ethical
37
38 423 approval is not required. The findings of this umbrella review will be disseminated through peer-
39
40 424 reviewed publications, participatory workshops, and academic conferences.
41
42

43 425 **Supplementary Information**

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45 426 Additional file 1. PRISMA-P Checklist.

46
47 427 Additional file 2. Search strategy for MEDLINE

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49 428 Additional file 3. Search strategy for Web of Science
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53 429 **Competing interests**

54
55 430 The authors declare that they have no competing interests.
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3 **431 Funding statement**
4

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6
7 433 research, including this umbrella review. She received a Trinity Research in Social Sciences
8
9
10 434 (TRiSS) Research Fellowship to conduct participatory workshops with youth as part of this
11
12 435 umbrella review. The funders did not play any role in design of this review.
13

14
15 **436 Authors' contributions**
16

17 437 AW and KH conceptualized and wrote the protocol with valuable inputs from QK. DB, ML, PC
18
19 438 will contribute to the screening, data extraction and analysis of this review as young co-researchers.
20
21 439 All authors have reviewed and approved the final manuscript.
22

23
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25

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31
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33
34 445 this umbrella review. We are very grateful to all the youth advisors and co-researchers who
35
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37 446 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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	1-2
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract	<input checked="" type="checkbox"/>	<input type="checkbox"/>	37
Authors					
Contact	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	<input checked="" type="checkbox"/>	<input type="checkbox"/>	6-12
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Support					
Sources	5a	Indicate sources of financial or other support for the review	<input checked="" type="checkbox"/>	<input type="checkbox"/>	431-435
Sponsor	5b	Provide name for the review funder and/or sponsor	<input checked="" type="checkbox"/>	<input type="checkbox"/>	431-435
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	<input checked="" type="checkbox"/>	<input type="checkbox"/>	435
INTRODUCTION					
Rationale	6	Describe the rationale for the review in the context of what is already known	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	367-374
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
	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)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-	<input type="checkbox"/>	<input checked="" type="checkbox"/>	

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	<input checked="" type="checkbox"/>	<input type="checkbox"/>	375-381
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	

For peer review only

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”)