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User involvement in adolescents' mental healthcare: Protocol for a systematic review

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601 **Title page**

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3 **User involvement in adolescents' mental healthcare: Protocol for a**
4 **systematic review**5 Petter Viksveen¹; Stig Erlend Bjønness¹; Siv Hilde Berg¹; Nicole Elizabeth Cardenas²; Julia Rose Game²;
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7

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3 22 **User involvement in adolescents' mental healthcare: Protocol for a**
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5 23 **systematic review**
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8 25 **ABSTRACT**
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11 27 **Introduction:** User involvement has become of growing importance in healthcare. The United
12 28 Nations state that adolescents have a right to be heard and user involvement in healthcare is a legal
13 29 right in some countries. Some research provides an insight into the field of user involvement in
14 30 somatic and mental healthcare for adults, but little is known about user involvement in adolescents'
15 31 mental healthcare and no overview of the existing research evidence exists.

16 32 **Objective:** To synthesize and assess the quality of the research literature reporting on experiences
17 33 with, effectiveness of and safety issues associated with user involvement for adolescents' mental
18 34 healthcare, for improvement of healthcare services and institutions, and for political decision-making
19 35 processes.

20 36 **Method:** A systematic literature search and assessment of published research in the field of user
21 37 involvement in adolescents' mental healthcare. Established guidelines are used for data extraction
22 38 (Cochrane Collaboration guidelines, STROBE, CASP), critical appraisal (Cochrane Collaboration
23 39 guidelines, PRECIS) and reporting of results (PRISMA, CONSORT, CASP). Confidence in the research
24 40 evidence will be assessed using the GRADE approach. Adolescents are included as co-researchers for
25 41 the planning and carrying out of this systematic review.

26 42 **Discussion:** This systematic review will provide an overview of the existing research literature and
27 43 thereby fill a knowledge gap. It may provide various stakeholders, including decision makers,
28 44 professionals, individuals and their families with an overview of existing knowledge in an
29 45 underexplored field of research.
30 46

31 47 **LAY ABSTRACT**
32 48

33 49 Individuals have a right to be heard and involved in decisions that affect their current and future
34 50 healthcare services. In several countries, this has become a legal right and it includes adolescents'
35 51 right to be involved in decisions affecting their mental healthcare. This is referred to as user
36 52 involvement. Some research has been carried out to assess user involvement in mental healthcare
37 53 for adults, but little is known about user involvement for adolescents' mental healthcare. We are
38 54 therefore planning to provide an overview of existing research reporting on adolescents and user
39 55 involvement for mental healthcare services. This includes user involvement affecting adolescents'

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3 56 own treatment for their mental health, and user involvement influencing existing healthcare services
4 57 and political decisions. Adolescents are taking part in the planning, carrying out and publication of
5
6 58 this research.
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9 60 **Keywords:** User involvement; adolescents; mental health; systematic review; protocol
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11 61

12 62 **Strengths and limitations of this study**

- 13 63 • This is the first systematic review assessing user involvement for adolescents' mental
14 64 healthcare
- 15 65 • Established guidelines are used for data retrieval, data extraction, critical appraisal, data
16 66 synthesis and reporting of results
- 17 67 • Adolescents are involved as co-researchers through all phases of the systematic review
- 18 68 • Wide inclusion criteria may represent challenges for synthesizing the research evidence,
19 69 although it will also provide a more extensive overview of the research literature
- 20 70 • We expect to find limited research evidence in this field, which may also limit the extent to
21 71 which we will be able to provide recommendations for clinical practice
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73 INTRODUCTION

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75 Mental health disorders affect a significant proportion of adolescents in countries all around the
76 world. On average, 13.4 % (CI 95 % 11.3-15.9) in the age groups up to 18 years suffer from mental
77 disorders, according to a meta-analysis of prevalence studies in 27 countries.¹ In many instances
78 these complaints result in functional impairment. The age group from 10 to 24 years represents 16 %
79 of all disability adjusted life years (DALYs) of all age groups and.²

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81 According to the United Nations and the European Convention of Human Rights, children and
82 adolescents have a right of access to high quality and safe healthcare services and their views must
83 be heard and considered in any matters affecting them.^{3,4} Although parents commonly have the
84 authority to make decisions on behalf of their children, some national legislative frameworks (e.g. in
85 Canada, Ireland and the United Kingdom) also emphasize children's right to be heard and actively
86 involved in decision-making concerning their own health.⁵ Adolescents at the age of 16 are in some
87 countries considered to be competent and have the right to consent to or refuse treatment. This may
88 in some instances extend down to the age of 12 (e.g. in Ireland, Netherlands, UK) or younger (e.g. in
89 Canada, New Zealand, South Africa), provided they are able to fully understand what the
90 interventions involve. Some of the basic principles underpinning national legislation and regulations
91 include respect, taking the adolescent seriously, encouraging cooperation and encouraging
92 adolescents to take responsibility for their own health.

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94 Patient- and person-centered or person-directed care with patient or service user involvement has
95 become increasingly common in various fields of healthcare and at various levels. The term patient-
96 centered care was initially described as focusing on the patient as a whole, including both physical
97 and psychological aspects.⁶ It requires a more active and participating role on the part of the
98 practitioner, compared to a more illness-oriented approach with uninvolved objective observation. In
99 later years, the understanding of patient-centered care has taken into account service users' needs,
100 priorities and expectations of healthcare services, and can lead to reorganization of services.⁷ A
101 person-centered approach moves one step further by taking the whole person into consideration,
102 including mental, emotional, spiritual and social needs, and in a person-directed approach individuals
103 take control of decisions affecting their own care.⁸

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105 Person-centered or person-directed care provides a context for user involvement, which can be
106 understood as engaging individual patients or users in processes of both planning and delivery of
107 their own healthcare services (at the individual level), as well as their influence on provision of health

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3 108 services in general (at the organizational or institutional level), and for political decision-making
4 109 processes.⁹ Users may here be understood as any person who is currently using or who may in the
5 110 future use care services. This does de facto include any person/citizen. User involvement is
6 111 encouraged through processes of collaboration with two-way communication, where professionals
7 112 provide individuals with sufficient and adequate information, by eliciting their views, opinions,
8 113 perceptions and perspectives. Such a form of user involvement requires reduction of power
9 114 differentials between service users and healthcare professionals, where professionals must be willing
10 115 to take users' views and wishes into account.¹⁰ When managed well, these processes may contribute
11 116 to shared decision-making and self-determination for patients' healthcare services, provided within a
12 117 context of person-centered or person-directed care.⁹
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21 119 The active involvement of service users in healthcare decision-making has the potential to contribute
22 120 to user empowerment and improvement of the quality and safety of healthcare systems.¹¹ National
23 121 legislation and regulation in many countries requires healthcare services to involve users in their own
24 122 treatment, as well as at an institutional/organizational and political level. This includes various areas
25 123 associated with mental healthcare, for example in development of healthcare policies and
26 124 strategies,¹² for implementation of clinical guidelines,¹³ in education of health professionals,¹⁴ and for
27 125 employment of healthcare staff and user-to-user panels.¹⁵ It has been suggested that users should be
28 126 involved at every mental healthcare service level.¹⁶
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35 128 Little is known about the existing research evidence reporting on user involvement for adolescents'
36 129 mental healthcare. A literature search carried out in 2012 with an aim to assess the existing evidence
37 130 of children's and adolescents' engagement in decision-making for their own healthcare, identified
38 131 only a handful of studies, in asthma, HIV, cancer, learning and behavior problems, and sun protection
39 132 behaviors.¹⁷ No systematic review has focused specifically on user involvement in adolescents'
40 133 mental healthcare.
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46 135 A number of important research questions need clarification, such as: What efforts are commonly
47 136 put into place to encourage user involvement in adolescents' mental healthcare and how do they
48 137 perceive such efforts? User involvement is commonly perceived to contribute positively to clinical
49 138 treatment outcomes and some research suggests shared decision-making for individuals' own
50 139 healthcare may be associated with improved health outcomes.^{18,19} But what are the results of the
51 140 overall research evidence for the effect of service user involvement on adolescents' mental health
52 141 outcomes? Furthermore, how does user involvement affect user safety? For example, adolescents
53 142 who currently self-harm have by some been found to have reduced decision-making skills,²⁰ thereby
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143 suggesting particular measures are needed to ensure safety in attempts to increase user involvement
144 in this group.

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146 This systematic review therefore aims to provide an overview of existing research reporting on
147 experiences with, and the effectiveness and safety issues associated with user involvement for
148 adolescents' mental healthcare.

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150 **Objectives**

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152 The objectives of this review are, in the field of adolescents' mental healthcare, to synthesize and to
153 assess the quality of the research literature reporting on experiences with, effectiveness of and
154 safety issues associated with user involvement:

155 A. At an individual level for adolescents' own healthcare;

156 B. At an organizational and institutional level for improvement of healthcare services and
157 institutions; and

158 C. At the political level for political decision-making processes.

159

160 **METHODS**

161 We will use pre-defined eligibility criteria and search strategies, and guidelines for data extraction,
162 critical appraisal, data synthesis and reporting of results.

163

164 **Eligibility criteria**

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166 The inclusion criteria for this systematic review are: Studies reporting on experiences with,
167 effectiveness of and safety issues associated with user involvement (intervention) in the planning,
168 delivery and development of adolescents' mental healthcare (participants). Users may be
169 adolescents or their caretakers. Mental healthcare may include preventive or therapeutic
170 interventions for diagnosed conditions or self-reported problems. User involvement may be aimed at
171 the individual level (for adolescents' own healthcare), at the organizational or institutional level (to
172 improve healthcare services/institutions), or at the political level (for making political decisions). It is
173 unlikely that the effectiveness of user involvement has been tested in randomized controlled trials.

174 We are therefore including non-randomized trials and studies (NRS). We are not limiting the
175 literature search to any specific research methods, as this may lead to missing studies in systematic
176 reviews including NRS.²¹ Studies may include any research design (qualitative or quantitative) used to

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3 177 answer the research questions of this review, and may or may not include comparators/control
4 178 groups (control). Outcomes will be reported according to the original trials and studies. User
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6 179 involvement may have been reported by adolescents, their caretakers, health professionals or other
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8 180 stakeholder groups. Adolescents will be defined as the age group from 10 to 19 years.²² Exclusion
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10 181 criteria: Debate, commentaries, editorials, conference abstracts, non-peer reviewed studies, studies
11
12 182 reporting on children (age below 10) or adults (age above 19). Conference abstracts will however be
13
14 183 considered to determine the risk of publication bias. Languages will be limited to English, French,
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16 184 German, Danish, Norwegian and Swedish. No year limitation will be set.
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186 **Search strategy**

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188 A systematic search of the following databases will be carried out: Academic Search Premier, BNI,
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190 CINAHL, Cochrane Library, EMBASE, MEDLINE, Oria, PubMed, PsycINFO, Scopus, SocINDEX, SveMed+
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192 and Web of Science (complete list in table 1). Reference lists of included studies will be hand
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194 searched for identification of additional titles. The grey literature will be searched using an advanced
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196 Google Scholar search limited to the first 50 results for each search string and through user/interest
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198 groups, experts and researchers in the field. An expert university librarian has been consulted as part
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200 of planning the literature search strategy. A draft search strategy for one electronic database
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202 (MEDLINE) is presented in Appendix A.

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Table 1. Literature sources

Databases

Academic Search Premier
BNI: British Nursing Index
CINAHL: Cumulative Index to Nursing and Allied Health Literature
Cochrane Library
EMBASE: Excerpta Medica Database
MEDLINE: National Library of Medicine
Oria
PubMed*: National Library of Medicine
PsycINFO: American Psychological Association
Scopus
SocINDEX: Database for Sociological Research
SveMed+: Medical data by the Karolinska Institute Library
Web of Science

Other sources

Google Scholar
User groups
Experts and researchers

197 * PubMed search will be limited to the last 2 years, as older titles are likely to be covered by MEDLINE.
 198
 199 A wide range of search terms will be used in order to identify relevant literature, as user involvement
 200 may include a whole range of different activities. Search strategies aimed at maximising sensitivity
 201 and specificity will be customized to databases, where possible using MeSH/Subject terms, Explode
 202 function, wildcard symbols and Boolean operators. A combination of groups of search terms will be
 203 used, including the service user group (adolescents), the field of health (psychiatry/mental health)
 204 and the field of research (involvement), as presented in table 2. Additional search terms identified
 205 through initial literature searches will be used if considered relevant.
 206

Table 2. Search terms

Area of health	Field of research			
Subject / MeSH Terms				
<u>User group & field of health</u>	<u>Field of research</u>			
Adolescent psychiatry	Clinical decision-making	Community participation		
Adolescent psychology	Consumer participation	Decision making		
	Cooperative behaviour	Decision making, organizational		
	Information sharing	Information dissemination		
	Patient participation	Personal autonomy		
	Public opinion	Self-determination		
Terms used in search of title or abstract				
<u>User group</u>	<u>Field of health</u>	<u>Field of research</u>		
Adolescents	Mental	Autonomy	Client-centred	Collaboration
Teenagers	Psychology	Consultation	Contribution	Decision-making
Youth	Psychiatry	Empowerment	Engagement	Governance
		Inclusion	Information sharing	Involvement
		Mutual agreement	Negotiation	Opinions
		Patient-centred	Participation	Partnership
		Perspectives	Peer support	Self-determination

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 208 A minimum of two reviewers will screen titles and abstracts to determine inclusion/exclusion of
 209 articles. All potentially relevant full text articles will be read and assessed according to the
 210 inclusion/exclusion criteria. In the event of continued doubt, a third reviewer will be included for
 211 consensus or majority vote decisions. Reasons for exclusion will be logged. Endnote (version X8) will
 212 be used to manage data records.

214 **Data extraction**

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3 216 Data will be extracted and input by one reviewer into an Excel spreadsheet using the Cochrane
4 217 Consumers and Communication Review Group's data extraction template for trials;²³ the STROBE
5 218 statement checklist for cohort, case-control and cross-sectional studies;²⁴ and the Critical Appraisal
6 219 Skills Programme (CASP) for qualitative studies.²⁵ A second reviewer will check the accuracy of input
7 220 data. Cross-references to article publications may be used, but authors of original trials and studies
8 221 will not be contacted for clarification as this may lead to too optimistic and biased responses.²⁶ For
9 222 studies reporting on the effectiveness of interventions, a main outcome will be identified as defined
10 223 by the authors of the original article. Reviewers will decide on which outcome measure to report in
11 224 the event that no main outcome has been defined by study authors, as well as any additional
12 225 outcomes of importance to users.
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21 **Critical appraisal**

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24 229 Including studies and trials using various research methods could potentially result in misleading
25 230 effect estimates.²¹ To avoid this, we will use the Cochrane Collaboration's guidelines to assess risk of
26 231 bias at the outcome level.²⁶ We will assess the risk of selection bias, performance bias, detection
27 232 bias, attrition bias and reporting bias. Particular attention will be paid to the potential influence of
28 233 confounding factors for NRS, as suggested by the Cochrane Collaboration.²¹ Moreover, we will assess
29 234 the risk of meta-bias by searching for unpublished studies in the grey literature; by comparing
30 235 protocols articles with results articles; and by assessing methods and results sections of individual
31 236 study articles. If there is a sufficient number of studies (min. 10) with variation in trial sizes (at least
32 237 one medium or large), funnel plot symmetry together with a regression analysis will be assessed to
33 238 consider risk of publication bias, as suggested by Sterne et al.²⁷ However, whether a trial is free of
34 239 bias does not address the question of its applicability and generalizability to end users, including
35 240 patients, clinicians and policy makers.²⁸ We will therefore assess the external validity of trials using
36 241 the PRECIS tool.²⁹ The Critical Appraisal Skills Programme (CASP) will be used for assessing qualitative
37 242 studies.²⁵
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48 244 The confidence in the evidence resulting from the identified research literature will be assessed using
49 245 the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach.³⁰
50 246 This will include assessment of the risk of bias, inconsistency, indirectness, imprecision, publication
51 247 bias and factors increasing the confidence in the effect of each outcome.
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56 **Data synthesis**

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3 251 The extent to which data will be synthesized, will depend on the degree of homogeneity of included
4 252 studies. We will determine consistency of the evidence by assessing the variability of trials. Particular
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6 253 attention will be paid to clinical aspects (e.g. interventions, clinical conditions) and research methods.
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8 254 The effect of heterogeneity will be quantified using the I^2 statistic to calculate variability across
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10 255 trials.³¹
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12 256
13 257 In the event of sufficient homogeneity, results of randomized trials will be presented collectively
14 258 through a meta-analysis, presenting effect estimates with standard errors or confidence intervals. A
15 259 summary statistic will be calculated for the main outcome in each trial, determining the risk ratio for
16 260 dichotomous outcomes and standardized mean differences for continuous outcomes (both with 95 %
17 261 confidence intervals). A weighted average will be calculated to determine the overall treatment
18 262 effect in the included trials. We expect at least some heterogeneity between trials and will therefore
19 263 apply a random effects model to estimate the mean of the distribution of effects. Analysis of sub-
20 264 groups will be considered for specific clinical conditions (e.g. depression, anxiety or psychosis), for
21 265 particular research methods (e.g. randomized controlled trials, cluster randomized trials or non-
22 266 randomized studies and trials), and if the I^2 statistic supersedes 40 %. For groups of NRS applying
23 267 similar study designs, summarized adjusted effect estimates will be presented (controlling for
24 268 confounding factors) as suggested by Reeves et al.²¹ Only a narrative summary will be developed in
25 269 the event of considerable heterogeneity ($I^2 > 75\%$). Dependent on a sufficient number of included
26 270 studies, qualitative studies will be synthesized.³² Some flexibility is needed with regards to choice of
27 271 the most suitable approach for the qualitative synthesis as this will depend on the available research
28 272 evidence, in particular with regards to the quality and heterogeneity of studies. We will therefore
29 273 make a final decision to determine the synthesis approach after collection of data, but will aim at
30 274 applying either a textual narrative synthesis or a thematic analytic synthesis approach.^{33,34}
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43 276 **Reporting results**

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46 278 The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement and
47 279 flow diagram will be used to report the result of literature searches.³⁵ Results of randomized
48 280 controlled trials will be reported according to the CONSORT statement,³⁶ for observational studies
49 281 the STROBE statement,²⁴ and for qualitative studies the CASP checklist.²⁵ Results of all studies will be
50 282 presented in tables, providing information on study design, results and quality of evidence. Separate
51 283 tables will be provided in the event of different subgroups of patients. We will report results
52 284 collectively for comparative (sufficiently homogenous) studies, grouped according to their associated
53 285 risk of bias. Results will be presented separately for randomized controlled trials and NRS. Moreover,
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3 286 the nature of the data will also warrant presentation of results according to research methods (e.g.
4 287 results of qualitative and quantitative studies will be reported separately). Information on
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6 288 methodological decisions made or modified after data collection will be reported. Moreover, we will
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8 289 report involvement of user/interest groups, experts and researchers.
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11 291 **Co-researchers and user involvement**

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14 293 Two adolescent co-researchers (NEC, JRG) have been involved in developing and writing the protocol
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16 294 for the systematic review and will be involved in the systematic review process. Mental health
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18 295 organizations have also been invited to the planning, carrying out and dissemination of the results of
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20 296 this systematic review.
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23 298 **DISCUSSION**

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26 300 User involvement has become a priority in healthcare systems in many countries, as it is considered a
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28 301 citizen right to be involved in decisions affecting one's own healthcare. Although several systematic
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30 302 reviews have summarized existing evidence in user involvement in health research for adults in
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32 303 general or in areas such as safety and education of mental health professionals,³⁷⁻³⁹ little is known
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34 304 about user involvement for adolescents' mental healthcare. This systematic review therefore aims to
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36 305 fill an existing knowledge gap. It will provide an insight into users' experiences, effectiveness of and
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38 306 safety issues associated with user involvement at an individual level for adolescents' own healthcare,
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40 307 at an organizational or institutional level for improvement of healthcare services and institutions, and
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42 308 at the political level for political decision-making processes. It may thereby provide information that
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44 309 can be valuable for several stakeholder groups, such as patients and their families, healthcare
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46 310 providers, clinicians and decision makers, as well as for developing research strategies to further
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48 311 knowledge in an underexplored field of research. This may include knowledge about ways in which
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50 312 users are involved in decision-making affecting their own healthcare and the influence of such
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52 313 involvement on their health outcomes. It can also provide information on user involvement affecting
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54 314 delivery and healthcare service policy decisions.
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58 316 There is considerable variation in the literature with regards to used terminology relating to user
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60 317 involvement. We have, in an attempt to capture the relevant research literature, included several
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62 318 search strategies using a variety of search terms. Moreover, we hope to capture most of the
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64 319 literature relevant to adolescents, although research carried out with varying age groups (single
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66 320 studies reporting on both children and adolescents, or adolescents and young people) may limit the

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3 321 breath of literature we will include in our review. The definition of “adolescents” varies within the
4 322 context of different national legislations and individual researchers’ and clinicians’ understanding.
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6 323 We have chosen UNICEF’s definition of adolescents, thereby including any studies reporting on
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8 324 results in the age group ranging from 10 to 19 years. The results of this review will therefore not be
9
10 325 applicable to children under the age of 10 or young persons above the age of 19 years.
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12 326

13 327 A limitation of this systematic review is the restriction to only six languages. Although we expect to
14 328 capture most of the published research literature through English language articles, and although
15 329 some evidence suggests reduced importance of non-English language articles for assessing the
16 330 effectiveness of interventions,⁴⁰ we cannot exclude the possibility that significant literature has been
17 331 published in other languages. We have added five languages in an attempt to limit the gaps in the
18 332 research evidence collected through our review. Our choice of languages is partly due to the strong
19 333 tradition user involvement has in some of these countries, but is nevertheless limited by our
20 334 available resources. The inclusion of a wide range of databases increases the likelihood of capturing
21 335 most of the relevant literature in this field of research. Moreover, the inclusion of databases more
22 336 specifically covering the Nordic literature will increase the chance of also capturing the evidence
23 337 published in these countries.
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32 339 **AUTHOR CONTRIBUTIONS**

33 340 PV is the guarantor. PV, SEB, SHB, NEC, JRG, KA and MS contributed to the development of the draft
34 341 manuscript. PV, SEB, SHB, KA and MS contributed to development of the search and assessment
35 342 strategies. PV, SEB, SHB, NEC, JRG, KA and MS read, provided feedback and approved the final
36 343 manuscript.
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44 347 strategies for our literature search.
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48 349 **COMPETING INTERESTS**

49 350 The authors have nothing to disclose.
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53 352 **SOURCES OF FINANCIAL OR OTHER SUPPORT**

54 353 None
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3 **Search strategy example for: User involvement in adolescents' mental**
4 **healthcare: Protocol for a systematic review**
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8 **MEDLINE** (1951 to Present)

9 **Search date:** 27.06.2017

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14 1. MH "adolescent psychiatry" 2,572
15 2. MH "adolescent psychology" 12,640
16 3. 1 OR 2 15,024
17 4. MH "community participation" 35,999
18 5. MH "clinical decision-making" 1,553
19 6. MH "information dissemination" 13,253
20 7. MH "patient participation" 21,034
21 8. MH "personal autonomy" 14,930
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34 **Result:** 209 titles for assessment
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PRISMA-P 2015 Checklist

This checklist has been adapted for use with protocol submissions to *Systematic Reviews* 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

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"/>	3-4
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	<input type="checkbox"/>	<input checked="" type="checkbox"/>	N/A
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract	<input type="checkbox"/>	<input checked="" type="checkbox"/>	N/A
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"/>	5-11
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	<input checked="" type="checkbox"/>	<input type="checkbox"/>	338-341
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"/>	N/A
Support					
Sources	5a	Indicate sources of financial or other support for the review	<input type="checkbox"/>	<input checked="" type="checkbox"/>	N/A
Sponsor	5b	Provide name for the review funder and/or sponsor	<input type="checkbox"/>	<input checked="" type="checkbox"/>	N/A
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	<input type="checkbox"/>	<input checked="" type="checkbox"/>	N/A
INTRODUCTION					
Rationale	6	Describe the rationale for the review in the context of what is already known	<input checked="" type="checkbox"/>	<input type="checkbox"/>	73-148
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to	<input checked="" type="checkbox"/>	<input type="checkbox"/>	150-158, 164-178



Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
		participants, interventions, comparators, and outcomes (PICO)			
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"/>	164-184
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"/>	186-195
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"/>	Appendix A
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"/>	207-219
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"/>	207-211
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"/>	215-224
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"/>	166-179
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"/>	178, 220-224
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"/>	229-237
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	<input checked="" type="checkbox"/>	<input type="checkbox"/>	250-254
	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 checked="" type="checkbox"/>	<input type="checkbox"/>	253-262
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-	<input checked="" type="checkbox"/>	<input type="checkbox"/>	262-268

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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"/>	267-273
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	232-237
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	243-246

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BMJ Open

User involvement in adolescents' mental healthcare: Protocol for a systematic review

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-018800.R1
Article Type:	Protocol
Date Submitted by the Author:	22-Sep-2017
Complete List of Authors:	Viksveen, Petter; University of Stavanger, SHARE - Centre for Resilience in Healthcare, Faculty of Health Sciences Bjønness, Stig; University of Stavanger, SHARE - Centre for Resilience in Healthcare, Faculty of Health Sciences Berg, Siv; Stavanger University Hospital, Department of psychiatry Cardenas, Nicole; St. Olav videregående skole, International Baccalaureate Game, Julia; St. Olav videregående skole, International Baccalaureate Aase, Karina; University of Stavanger, SHARE - Centre for Resilience in Healthcare, Faculty of Health Sciences; Stavanger University Hospital, Regional Centre for Age-related Medicine and Coordination Storm, Marianne; University of Stavanger, SHARE - Centre for Resilience in Healthcare, Faculty of Health Sciences
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Paediatrics, Patient-centred medicine
Keywords:	User involvement, Adolescents, MENTAL HEALTH, Systematic review, Protocol

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1 **Title page**

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3 **User involvement in adolescents' mental healthcare: Protocol for a**
4 **systematic review**

5 Petter Viksveen¹; Stig Erlend Bjønness¹; Siv Hilde Berg²; Nicole Elizabeth Cardenas³; Julia Rose Game³;
6 Karina Aase¹; Marianne Storm¹.

7

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24 **User involvement in adolescents' mental healthcare: Protocol for a** 25 **systematic review**

27 **ABSTRACT**

28
29 **Introduction:** User involvement has become of growing importance in healthcare. The United
30 Nations state that adolescents have a right to be heard and user involvement in healthcare is a legal
31 right in many countries. Some research provides an insight into the field of user involvement in
32 somatic and mental healthcare for adults, but little is known about user involvement in adolescents'
33 mental healthcare and no overview of the existing research evidence exists.

34 **Methods and analysis:** The aim of this systematic review is to provide an overview of existing
35 research reporting on experiences with, and the effectiveness and safety issues associated with user
36 involvement for adolescents' mental healthcare, at the individual and organizational level.
37 A systematic literature search and assessment of published research in the field of user involvement
38 in adolescents' mental healthcare. Established guidelines will be used for data extraction (Cochrane
39 Collaboration guidelines, STROBE, CASP), critical appraisal (Cochrane Collaboration guidelines,
40 PRECIS) and reporting of results (PRISMA, CONSORT, CASP). Confidence in the research evidence will
41 be assessed using the GRADE approach. Adolescents are included as co-researchers for the planning
42 and carrying out of this systematic review. This systematic review will provide an overview of the
43 existing research literature and thereby fill a knowledge gap. It may provide various stakeholders,
44 including decision makers, professionals, individuals and their families with an overview of existing
45 knowledge in an underexplored field of research.

46 **Ethics and dissemination:** Ethics approval is not required for this systematic review as we are not
47 collecting primary data. The results will be published in a peer-reviewed journal and at conference
48 presentations, and will be shared with stakeholder groups.

49
50 **Keywords:** User involvement; adolescents; mental health; systematic review; protocol

52 **Strengths and limitations of this study**

- 53 • This is the first systematic review assessing user involvement for adolescents' mental
54 healthcare
- 55 • Established guidelines are used for data retrieval, data extraction, critical appraisal, data
56 synthesis and reporting of results
- 57 • Adolescents are involved as co-researchers through all phases of the systematic review

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- Wide inclusion criteria may represent challenges for synthesizing the research evidence, although it will also provide a more extensive overview of the research literature
- We expect to find limited research evidence in this field, which may also limit the extent to which we will be able to provide recommendations for clinical practice

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63 INTRODUCTION

64

65 Mental health disorders affect a significant proportion of adolescents in countries all around the
66 world. A meta-analysis of prevalence studies in 27 countries indicated that on average 13.4 % (CI 95
67 % 11.3-15.9) in the age groups up to 18 years live with mental disorders.¹ In many instances these
68 disorders result in functional impairment. The age group from 10 to 24 years represents 16 % of all
69 disability adjusted life years (DALYs) of all age groups.²

70

71 According to the United Nations and the European Convention of Human Rights, children and
72 adolescents have a right of access to high quality and safe healthcare services and their views must
73 be heard and considered in any matters affecting them.^{3,4} Although parents commonly have the
74 authority to make decisions on behalf of their children, some national legislative frameworks (e.g. in
75 Canada, Ireland and the United Kingdom) also emphasize children's right to be heard and actively
76 involved in decision-making concerning their own health.⁵ Adolescents at the age of 16 are in some
77 countries considered to be competent and have the right to consent to or refuse treatment. This may
78 in some instances extend down to the age of 12 (e.g. in Ireland, Netherlands, UK) or younger (e.g. in
79 Canada, New Zealand, South Africa), provided they are able to fully understand what the
80 interventions involve. Some of the basic principles underpinning national legislation and regulations
81 include respect, taking the adolescent seriously, encouraging cooperation and encouraging
82 adolescents to take responsibility for their own health.

83

84 Patient- and person-centered or person-directed care with patient or service user involvement has
85 become increasingly common in various fields of healthcare and at various levels. The term patient-
86 centered care was initially described as focusing on the patient as a whole, including both physical
87 and psychological aspects.⁶ It requires a more active and participating role on the part of the
88 practitioner, compared to a more illness-oriented approach with uninvolved objective observation. In
89 later years, the understanding of patient-centered care has taken into account service users' needs,
90 priorities and expectations of healthcare services, and can lead to reorganization of services.⁷ A
91 person-centered approach moves one step further by taking the whole person into consideration,
92 including mental, emotional, spiritual and social needs, and in a person-directed approach individuals
93 take control of decisions affecting their own care.⁸

94

95 Person-centered or person-directed care provides a context for user involvement, which can be
96 understood as engaging individual patients or users in processes of both planning and delivery of
97 their own healthcare services (at the individual level), as well as their influence on provision of health

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3 98 services in general (at the organizational or institutional level), and for political decision-making
4 99 processes.⁹ Users may here be understood as any person who is currently using or who may in the
5
6 100 future use care services. This does de facto include any person/citizen. User involvement is
7
8 101 encouraged through processes of collaboration with two-way communication, where professionals
9
10 102 provide individuals with sufficient and adequate information, by eliciting their views, opinions,
11
12 103 perceptions and perspectives. Such a form of user involvement requires reduction of power
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14 104 differentials between service users and healthcare professionals, where professionals must be willing
15
16 105 to take users' views and wishes into account.¹⁰ When managed well, these processes may contribute
17
18 106 to shared decision-making and self-determination for patients' healthcare services, provided within a
19
20 107 context of person-centered or person-directed care.⁹
21 108

22 109 The active involvement of service users in healthcare decision-making has the potential to contribute
23
24 110 to user empowerment and improvement of the quality and safety of healthcare systems.¹¹ National
25
26 111 legislation and regulation in many countries requires healthcare services to involve users in their own
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28 112 treatment, as well as at an institutional/organizational and political level. This includes various areas
29
30 113 associated with mental healthcare, for example in development of healthcare policies and
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32 114 strategies,¹² for implementation of clinical guidelines,¹³ in education of health professionals,¹⁴ and for
33
34 115 employment of healthcare staff and user-to-user panels.¹⁵ It has been suggested that users should be
35
36 116 involved at every mental healthcare service level.¹⁶
37 117

38 118 Little is known about the existing research evidence reporting on user involvement for adolescents'
39
40 119 mental healthcare. A literature search carried out in 2012 with an aim to assess the existing evidence
41
42 120 of children's and adolescents' engagement in decision-making for their own healthcare, identified
43
44 121 only a handful of studies, in asthma, HIV, cancer, learning and behavior problems, and sun protection
45
46 122 behaviors.¹⁷ No systematic review has focused specifically on user involvement in adolescents'
47
48 123 mental healthcare.
49 124

50 125 Various definitions of adolescence exist.¹⁸⁻²⁰ The term "adolescence" comes from Latin and refers to
51
52 126 "growing up". This phase of life involves the transition from childhood to adulthood. The time for the
53
54 127 onset and conclusion of adolescence varies between individuals. In light of this, it may seem artificial
55
56 128 to limit the age range when assessing mental healthcare services for adolescents. However, mental
57
58 129 healthcare services for adolescents are commonly provided from the start of secondary school,
59
60 130 typically around the age of 12 or 13 years. Moreover, in many countries the age of 18 is considered
131
132 131 the legal transition into adulthood. The age range from 13 to 18 years corresponds to the MeSH
132
133 132 definition of adolescence (Unique ID: D000293).

133

134 A number of important research questions need clarification, such as: What efforts are commonly
135 put into place to encourage user involvement in adolescents' mental healthcare and how do they
136 perceive such efforts? User involvement is commonly perceived to contribute positively to clinical
137 treatment outcomes and some research suggests shared decision-making for individuals' own
138 healthcare may be associated with improved health outcomes.^{21,22} But what are the results of the
139 overall research evidence for the effect of service user involvement on adolescents' mental health
140 outcomes? Furthermore, how does user involvement affect patient safety? For example, some have
141 found that adolescents who currently self-harm have reduced decision-making skills.²³ Are particular
142 measures needed to ensure the safety of this group when increasing user involvement?

143

144 **Objectives**

145

146 This systematic review aims to provide an overview of existing research reporting on experiences
147 with, and the effectiveness and safety issues associated with user involvement for adolescents'
148 mental healthcare.

149

150 The objectives of this review are:

- 151 A. To assess the experiences with user involvement for adolescents' mental healthcare at the
152 individual and organizational level.
- 153 B. To assess the effectiveness of user involvement for adolescents' mental healthcare at the
154 individual and organizational level.
- 155 C. To assess safety issues associated with user involvement for adolescents' mental healthcare at
156 the individual and organizational level.

157

158 **METHODS**

159 We will use pre-defined eligibility criteria and search strategies, and guidelines for data extraction,
160 critical appraisal, data synthesis and reporting of results.

161

162 **Eligibility criteria**

163

164 The inclusion criteria for this systematic review are: Studies reporting on experiences with,
165 effectiveness of and safety issues associated with user involvement (intervention) in the planning,
166 delivery and development of mental healthcare for adolescents (participants). Mental healthcare

167 may include preventive or therapeutic interventions for diagnosed conditions or self-reported
 168 problems. User involvement may be aimed at the individual level (for adolescents' own mental
 169 healthcare) or at the organizational or institutional level (to improve mental healthcare
 170 services/institutions). It is unlikely that the effectiveness of user involvement has been tested in
 171 randomized controlled trials. We will therefore include non-randomized trials and studies (NRS).
 172 Additionally, we will not limit the literature search to any specific research methods, as this may lead
 173 to missing studies in systematic reviews including NRS.²⁴ Studies may include any research design
 174 (qualitative or quantitative) used to answer the research questions of this review, and may or may
 175 not include comparators/control groups (control). Outcomes will be reported according to the
 176 original trials and studies. Adolescents' user involvement may have been reported by adolescents,
 177 their caretakers, health professionals or other stakeholder groups. Adolescents will be defined as the
 178 age group from 13 to 18 years (MeSH Unique ID: D000293). Studies reporting on adolescents and
 179 children or adults will be included if data for adolescents can be extracted and analysed separately.
 180 Results of the peer-reviewed and the grey literature will be reported separately. Exclusion criteria:
 181 Debate, commentaries, editorials, studies reporting on children (age below 13) or adults (age above
 182 18). Languages will be limited to English, French, German, Danish, Norwegian and Swedish. The
 183 literature will be limited to the last 15 years (2002–2017).

185 Search strategy

186
 187 A systematic search of the following databases will be carried out: Academic Search Premier, BNI,
 188 CINAHL, Cochrane Library, EMBASE, MEDLINE, PubMed, PsycINFO, Scopus, SocINDEX, SveMed+ and
 189 Web of Science (complete list in table 1). Reference lists of included studies will be hand searched for
 190 identification of additional titles. The grey literature will be searched using an advanced Google
 191 Scholar search limited to the first 50 results for each search string and through user/interest groups,
 192 experts and researchers in the field. An expert university librarian has been consulted as part of
 193 planning the literature search strategy. A draft search strategy for one electronic database
 194 (MEDLINE) is presented in Appendix A.

195

Table 1. Literature sources

Databases (with dates of coverage)
Academic Search Premier (2002–2017)
BNI: British Nursing Index (2002–2017)
CINAHL: Cumulative Index to Nursing and Allied Health Literature (2002–2017)
Cochrane Library (2002–2017)

EMBASE: Excerpta Medica Database (2002–2017)
 MEDLINE: National Library of Medicine (2002–2017)
 PubMed*: National Library of Medicine (2016–2017)
 PsycINFO: American Psychological Association (2002–2017)
 Scopus (2002–2017)
 SocINDEX: Database for Sociological Research (2002–2017)
 SveMed+: Medical data by the Karolinska Institute Library (2002–2017)
 Web of Science (2002–2017)

Other sources

Google Scholar
 User groups
 Experts and researchers

196 * PubMed search will be limited to the last 2 years, as older titles are likely to be covered by MEDLINE.

197

198 A wide range of search terms will be used in order to identify relevant literature, as user involvement
 199 may include a whole range of different activities. Search strategies aimed at maximising sensitivity
 200 and specificity will be customized to databases, where possible using MeSH/Subject terms, Explode
 201 function, wildcard symbols and Boolean operators. A combination of groups of search terms will be
 202 used, including the service user group (adolescents), the field of health (psychiatry/mental health)
 203 and the field of research (involvement), as presented in table 2.

204

Table 2. Search terms

Area of health	Field of research			
Subject / MeSH Terms				
<u>User group & field of health</u>	<u>Field of research</u>			
Adolescent psychiatry	Clinical decision-making	Community participation		
Adolescent psychology	Consumer participation	Decision making		
	Cooperative behaviour	Decision making, organizational		
	Information sharing	Information dissemination		
	Patient participation	Personal autonomy		
	Public opinion	Self-determination		
Terms used in search of title				
<u>User group</u>	<u>Field of health</u>	<u>Field of research</u>		
Adolescents	Mental	Autonomy	Client-centred	Collaboration
Teenagers	Psychology	Consultation	Contribution	Decision-making
Youth	Psychiatry	Empowerment	Engagement	Governance
		Inclusion	Information sharing	Involvement
		Mutual agreement	Negotiation	Opinions
		Patient-centred	Participation	Partnership
		Perspectives	Peer support	Self-determination

205

1
2
3 206 A minimum of two reviewers will screen titles and abstracts to determine inclusion/exclusion of
4 207 articles. All potentially relevant full text articles will be read and assessed by at least two reviewers
5
6 208 according to the inclusion/exclusion criteria. In the event of continued doubt, a third reviewer will be
7
8 209 included for consensus or majority vote decisions. Reasons for exclusion will be logged. Endnote
9
10 210 (version X8) will be used to manage data records.
11

12 **Data extraction**

13
14 213
15
16 214 Data will be extracted and input by one reviewer into an Excel spreadsheet using the Cochrane
17
18 215 Consumers and Communication Review Group's data extraction template for trials;²⁵ the STROBE
19
20 216 statement checklist for cohort, case-control and cross-sectional studies;²⁶ and the Critical Appraisal
21
22 217 Skills Programme (CASP) for qualitative studies.²⁷ A second reviewer will check the accuracy of input
23
24 218 data. Cross-references to article publications may be used, but authors of original trials and studies
25
26 219 will not be contacted for clarification as this may lead to too optimistic and biased responses.²⁸ For
27
28 220 studies reporting on the effectiveness of interventions, a main outcome will be identified as defined
29
30 221 by the authors of the original article. Reviewers will decide on which outcome measure to report in
31
32 222 the event that no main outcome has been defined by study authors, as well as any additional
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34 223 outcomes of importance to users.
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37 **Critical appraisal**

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43 227 Including studies and trials using various research methods could potentially result in misleading
44
45 228 effect estimates.²⁴ To avoid this, we will use the Cochrane Collaboration's guidelines to assess risk of
46
47 229 bias at the outcome level.²⁸ We will assess the risk of selection bias, performance bias, detection
48
49 230 bias, attrition bias and reporting bias. Particular attention will be paid to the potential influence of
50
51 231 confounding factors for NRS, as suggested by the Cochrane Collaboration.²⁴ Moreover, we will assess
52
53 232 the risk of meta-bias by searching for unpublished studies in the grey literature; by comparing
54
55 233 protocols articles with results articles; and by assessing methods and results sections of individual
56
57 234 study articles. If there is a sufficient number of studies (min. 10) with variation in trial sizes (at least
58
59 235 one medium or large), funnel plot symmetry together with a regression analysis will be assessed to
60
236 consider risk of publication bias, as suggested by Sterne et al.²⁹ However, whether a trial is free of
237 bias does not address the question of its applicability and generalizability to end users, including
238 patients, clinicians and policy makers.³⁰ We will therefore assess the external validity of trials using
239 the PRECIS tool.³¹ The Critical Appraisal Skills Programme (CASP) will be used for assessing qualitative
240 studies.²⁷

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The confidence in the evidence resulting from the identified research literature will be assessed using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach.³²

This will include assessment of the risk of bias, inconsistency, indirectness, imprecision, publication bias and factors increasing the confidence in the effect of each outcome.

Data synthesis

The extent to which data will be synthesized, will depend on the degree of homogeneity of included studies. We will determine consistency of the evidence by assessing the variability of trials. Particular attention will be paid to clinical aspects (e.g. interventions, clinical conditions) and research methods.

The effect of heterogeneity will be quantified using the I^2 statistic to calculate variability across trials.³³

In the event of sufficient homogeneity, results of randomized trials will be presented collectively through a meta-analysis, presenting effect estimates with standard errors or confidence intervals. A summary statistic will be calculated for the main outcome in each trial, determining the risk ratio for dichotomous outcomes and standardized mean differences for continuous outcomes (both with 95 % confidence intervals). A weighted average will be calculated to determine the overall treatment effect in the included trials. We expect at least some heterogeneity between trials and will therefore apply a random effects model to estimate the mean of the distribution of effects. Analysis of subgroups will be considered for specific clinical conditions (e.g. depression, anxiety or psychosis), for particular research methods (e.g. randomized controlled trials, cluster randomized trials or non-randomized studies and trials), and if the I^2 statistic supersedes 40 %. For groups of NRS applying similar study designs, summarized adjusted effect estimates will be presented (controlling for confounding factors) as suggested by Reeves et al.²⁴ Only a narrative summary will be developed in the event of considerable heterogeneity ($I^2 > 75\%$). Dependent on a sufficient number of included studies, qualitative studies will be synthesized.³⁴ Some flexibility is needed with regards to choice of the most suitable approach for the qualitative synthesis as this will depend on the available research evidence, in particular with regards to the quality and heterogeneity of studies. We will therefore make a final decision to determine the synthesis approach after collection of data, but will aim at applying either a textual narrative synthesis or a thematic analytic synthesis approach.^{35,36}

Reporting results

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2
3 276 The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement and
4 277 flow diagram will be used to report the result of literature searches.³⁷ Results of randomized
5 278 controlled trials will be reported according to the CONSORT statement,³⁸ for observational studies
6 279 the STROBE statement,²⁶ and for qualitative studies the CASP checklist.²⁷ Results of all studies will be
7 280 presented in tables, providing information on study design, results and quality of evidence. Separate
8 281 tables will be provided in the event of different subgroups of patients. We will report results
9 282 collectively for comparative (sufficiently homogenous) studies, grouped according to their associated
10 283 risk of bias. Results will be presented separately for randomized controlled trials and NRS. Moreover,
11 284 the nature of the data will also warrant presentation of results according to research methods (e.g.
12 285 results of qualitative and quantitative studies will be reported separately). Information on
13 286 methodological decisions made or modified after data collection will be reported. Moreover, we will
14 287 report involvement of user/interest groups, experts and researchers.
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24 289 **Co-researchers and user involvement**

25 290
26 291 Two adolescent co-researchers (NEC, JRG) have been involved in developing and writing the protocol
27 292 for the systematic review and will be involved in the systematic review process. They were invited to
28 293 participate in the systematic review as part of the InvolveMENT research project, which they are
29 294 already involved in. The InvolveMENT project aims to assess factors affecting adolescents' mental
30 295 health and to develop and assess the effectiveness of an e-intervention. Mental health organizations
31 296 have also been invited to the planning (but have not yet participated), carrying out and dissemination
32 297 of the results of this systematic review.
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40 299 The adolescent co-researchers' role and contribution:

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42 301 We have participated in the process of developing the systematic review and we will contribute in
43 302 the review process and for publishing the results. We have agreed to be asked for our opinion on
44 303 articles the other researchers consider including, their evaluation of the content and quality of the
45 304 articles, and how results will be reported. We will also publish a lay summary of the results on a
46 305 Facebook site we are setting up for the research project.
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53 307 We expressed our interest in being part of the InvolveMENT project team following a presentation
54 308 that was given at our high school in January 2017 by a researcher (PV). Since then we have had
55 309 monthly meetings and have been introduced to the field of adolescent mental health research,
56 310 research terminology and methodology, and the systematic review process. We have also
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3 311 participated at a University workshop to learn the basics of systematic reviews and literature
4 312 searches. We have asked not to be referred to as “user representatives”, as we are not participants
5
6 313 in the research and the term can carry stigma. Instead we asked to be referred to as “adolescent
7
8 314 representatives”. It was later decided we should be re-defined as “co-researchers” as we became
9
10 315 more actively involved in the research. For examples, we have carried out a questionnaire survey in
11
12 316 cooperation with one of the researchers (PV) to learn about the prevalence of mental disorders and
13
14 317 stress in teenagers and their use of mental healthcare services. This research was started in June this
15
16 318 year and is still ongoing. We plan to present the results to the students who took part in the survey,
17
18 319 teachers and school nurses, and we hope it will help to reduce some of the stigma surrounding
19
20 320 mental health and to improve mental health services.
21

22 322 DISCUSSION

23
24 324 User involvement has become a priority in healthcare systems in many countries, as it is considered a
25
26 325 citizen right to be involved in decisions affecting one’s own healthcare. Although several systematic
27
28 326 reviews have summarized existing evidence in user involvement in health research for adults in
29
30 327 general or in areas such as safety and education of mental health professionals,³⁹⁻⁴¹ no review has
31
32 328 been published assessing user involvement for adolescents’ mental healthcare. This systematic
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34 329 review therefore aims to fill an existing knowledge gap. It will provide an insight into users’
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36 330 experiences, effectiveness of and safety issues associated with user involvement at an individual
37
38 331 level for adolescents’ own mental healthcare, at an organizational or institutional level for
39
40 332 improvement of mental healthcare services and institutions, and at the political level for political
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42 333 decision-making processes. It may thereby provide information that can be valuable for several
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44 334 stakeholder groups, such as patients and their families, healthcare providers, clinicians and decision
45
46 335 makers, as well as for developing research strategies to further knowledge in an underexplored field
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48 336 of research. This may include knowledge about ways in which users are involved in decision-making
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50 337 affecting their own mental healthcare and the influence of such involvement on their mental health
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52 338 outcomes. It can also provide information on user involvement affecting delivery and mental
53
54 339 healthcare service policy decisions.
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56
57 341 There are some potential limitations to this systematic review. There is considerable variation in the
58
59 342 literature with regards to used terminology relating to user involvement. This contributes to a risk of
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343 missing relevant studies. We have, in an attempt to capture the relevant research literature, included
344 several search strategies using a variety of search terms. Moreover, not including search terms
345 relating to specific mental diagnoses contributes to a risk of missing relevant studies. We are

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2
3 346 however interested in reviewing the mental health research literature overall, and not focus on a
4 347 limited number of specific conditions. Inclusion of the breath of different diagnoses would also
5
6 348 contribute to an unmanageable number of titles to screen. Moreover, we hope to capture most of
7
8 349 the literature relevant to adolescents, although research carried out with varying age groups (single
9
10 350 studies reporting on both children and adolescents, or adolescents and young people) may limit the
11
12 351 breath of literature we will include in our review. The definition of “adolescents” varies within the
13
14 352 context of different national legislations and individual researchers’ and clinicians’ understanding. .
15
16 353 We have limited this literature review to adolescents in the age range from 13 to 18 years. It could be
17
18 354 argued for a different age span for adolescents, e.g. using UNICEF’s definition and the results of this
19
20 355 review will not be applicable to children under the age of 13 or young persons above the age of 18
21
22 356 years. We do however think that our search strategy will help us to capture most of the relevant
23
24 357 literature that is of relevance to user involvement in adolescents’ mental healthcare.
25
26 358

27
28 359 Another limitation of this systematic review is the restriction to only six languages. Although we
29
30 360 expect to capture most of the published research literature through English language articles, and
31
32 361 although some evidence suggests reduced importance of non-English language articles for assessing
33
34 362 the effectiveness of interventions,⁴² we cannot exclude the possibility that significant literature has
35
36 363 been published in other languages. We have selected six languages in an attempt to limit the gaps in
37
38 364 the research evidence collected through our review. Our choice of languages is partly due to the
39
40 365 strong tradition user involvement has in some of these countries, but is nevertheless limited by our
41
42 366 available resources. The inclusion of a wide range of databases increases the likelihood of capturing
43
44 367 most of the relevant literature in this field of research. Moreover, the inclusion a database more
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46 368 specifically covering the Nordic literature will increase the chance of also capturing the evidence
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48 369 published in these countries.
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51
52 371 Our systematic review team includes adolescent co-researchers. Others have suggested public or
53
54 372 user involvement may contribute significantly to various stages of the systematic review process.⁴³⁻⁴⁷
55
56 373 It has however been pointed out that such involvement can in some cases be tokenistic,⁴⁷ and that
57
58 374 power differentials may affect the usefulness of such involvement.⁴³ We argue that the involvement
59
60 375 of adolescents as co-researchers may contribute by strengthening the usefulness of the review for
376 different stakeholder groups, in particular for adolescents themselves.
377

378 **AUTHOR CONTRIBUTIONS**

379 PV is the guarantor. PV, SEB, SHB, NEC, JRG, KA and MS contributed to the development of the draft
380 manuscript. PV, SEB, SHB, KA and MS contributed to development of the search and assessment

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3 381 strategies. JRG and NEC developed the section reporting on Co-researchers and user involvement.
4 382 PV, SEB, SHB, NEC, JRG, KA and MS read, provided feedback and approved the final manuscript.
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6 383

7
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10 386 strategies for our literature search.
11
12 387

13
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15 389 The authors have nothing to disclose.
16
17 390

18
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21
22 393

23
24 394 **REFERENCES**

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Search strategy example for: User involvement in adolescents' mental healthcare: Protocol for a systematic review

MEDLINE (2002 to 2017)

Search date: 04.08.2017. Limiters – Age Related: Adolescent: 13-18 years

1. (SU adolescent psychology) OR (SU adolescent psychiatry): 15,127
2. (SU clinical decision making) OR (SU community participation) OR (SU consumer participation) OR (SU information dissemination) OR (SU information sharing) OR (SU patient participation) OR (SU personal autonomy) OR (SU self-determination) OR (SU decision making) OR (SU cooperative behavior) OR (SU public opinion): 203,407
3. 1 AND 2: 545
4. (TI adolescen*) OR (TI teen*) OR (TI youth*): 163,384
5. (TI mental) OR (TI psycholog*) OR (TI psychiatr*): 232,363
6. (TI autonom*) OR (TI client-centred) OR (TI collaborat*) OR (TI consultat*) OR (TI contribut*) OR (TI decision making) OR (TI empower*) OR (TI engag*) OR (TI governance) OR (TI inclusi*) OR (TI information sharing) OR (TI involv*) OR (TI mutual agreement) OR (TI negotiat*) OR (TI opinion*) OR (TI patient-centred) OR (TI participat*) OR (TI partnership*) OR (TI perspective*) OR (TI peer support) OR (TI self-determination): 546,436
7. 9 AND 10 AND 11: 416
8. 3 OR 7: 952
9. 3 OR 7 Narrow by SubjectAge: - adolescent: 13-18 years: 817

Result: 817 titles for assessment

PRISMA-P 2015 Checklist

This checklist has been adapted for use with protocol submissions to *Systematic Reviews* 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

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"/>	3-4
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	<input type="checkbox"/>	<input checked="" type="checkbox"/>	N/A
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract	<input type="checkbox"/>	<input checked="" type="checkbox"/>	N/A
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"/>	5-11
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	<input checked="" type="checkbox"/>	<input type="checkbox"/>	338-341
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"/>	N/A
Support					
Sources	5a	Indicate sources of financial or other support for the review	<input type="checkbox"/>	<input checked="" type="checkbox"/>	N/A
Sponsor	5b	Provide name for the review funder and/or sponsor	<input type="checkbox"/>	<input checked="" type="checkbox"/>	N/A
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	<input type="checkbox"/>	<input checked="" type="checkbox"/>	N/A
INTRODUCTION					
Rationale	6	Describe the rationale for the review in the context of what is already known	<input checked="" type="checkbox"/>	<input type="checkbox"/>	73-148
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to	<input checked="" type="checkbox"/>	<input type="checkbox"/>	150-158, 164-178



Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
		participants, interventions, comparators, and outcomes (PICO)			
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"/>	164-184
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"/>	186-195
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"/>	Appendix A
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"/>	207-219
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"/>	207-211
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"/>	215-224
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"/>	166-179
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"/>	178, 220-224
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"/>	229-237
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	<input checked="" type="checkbox"/>	<input type="checkbox"/>	250-254
	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 checked="" type="checkbox"/>	<input type="checkbox"/>	253-262
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-	<input checked="" type="checkbox"/>	<input type="checkbox"/>	262-268

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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"/>	267-273
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	232-237
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	243-246

peer review only

