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Outcomes valued by people living with dementia and their carers: Protocol for a qualitative systematic review and synthesis

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Redacted from Authors' contributions

LB, CB, AW and LR drafted the protocol. CB, LR, and AW conceived the initial study idea and AW, CB and GB completed preliminary work to inform its development. All authors made substantial contributions to the design of the study, revised the manuscript critically for important intellectual content, and approved the final manuscript. LR is the guarantor of the review.

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Abstract

Introduction Growing numbers of interventions are being developed to support people and families living with dementia, but the extent to which they address the areas of most importance to the intended recipients is unclear. This qualitative review will synthesise outcomes identified as important from the perspectives of people with dementia and their care partners, both for themselves and each other.

Methods and analysis The review will employ thematic synthesis methodology. Studies from 1990 or later will be eligible if they include qualitative data on the views of people living with dementia or their care partners on valued outcomes or the lived experience of dementia. Databases to be searched include MEDLINE, CINAHL, PsycInfo and Social Sciences Premium Collection, in addition to systematically gathered grey literature. Rayyan QCRI software will be used to manage the screening processes and NVivo software will be used to manage data extraction and analysis. The review will also critically evaluate the extent to which international recommendations address the areas of importance to people living with dementia and their families. The findings will be of relevance to researchers, policy makers, and providers and commissioners of dementia services. The protocol is written in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols guidelines.

Ethics and dissemination As the methodology of this study consists of collecting data from publicly available articles, it does not require ethical approval. We will share the results through conference presentations and an open access publication in a peer-reviewed journal. Our mixed stakeholder involvement group will advise on dissemination to non-academic audiences.

Strengths and limitations of this study

- A strength of the study will be the inclusion of studies of the lived experience of dementia which are likely to highlight important outcomes but have not been included in previous reviews
- The findings will provide new insight into the concordance between outcomes valued by people living with dementia and care partners, for themselves and for each other
- We carried out a comprehensive examination of qualitative synthesis methodologies and quality appraisal tools to select the most appropriate to this review
- Studies not published in English will not be included in this review but will be labelled and recorded.

Word count: 3100 including abstract, excluding title page, references, figures and tables

Introduction

There is an ongoing shift in UK and international policy from improving diagnostic rates of dementia to enhancing post-diagnostic support to enable people to 'live well' with dementia (1, 2) or to live a life with meaning and dignity.(3) In order to achieve these emerging policy aims, we need to understand what these abstract concepts mean to people living with dementia and their care partners, caregivers or carers (hereafter care partners) and translate them into specific outcomes which can be used to inform and evaluate interventions. Involving people living with dementia and their care

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3 partners in this process of translation is essential to ensure that interventions focus on the outcomes
4 valued by the intended beneficiaries.(4)
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6 Insight into outcomes prioritised by people living with dementia and care partners is provided by
7 recent studies to develop core outcome sets. To date, core outcome sets have been developed for
8 disease modification trials,(5) psychosocial interventions,(6) physical activity,(7) medication
9 management,(8) and nonpharmacological community-based health and social care interventions.(9)
10 The extent to which the views of people living with dementia have been included in these studies
11 varies although some have developed innovative methods to ensure their perspectives are
12 captured.(8, 9). This has sometimes highlighted the discrepancies in outcomes valued by people living
13 with dementia and professionals.(7, 8) The emphasis on developing core outcome sets for use with
14 specific populations and types of interventions, however, limits the value of these studies in
15 understanding the full range of outcomes valued by people living with dementia.
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19 Data from quantitative studies comparing self- and proxy-reported ratings of quality of life also
20 suggest that people with dementia and care partners may not share the same priorities when
21 considering quality of life. Care partners consistently rate quality of life lower than the person living
22 with dementia whom they support.(10-12). While quantitative studies have sought to identify
23 demographic and clinical factors contributing to this discrepancy. (10-12), several authors have
24 highlighted the need for qualitative studies to increase our understanding of how quality of life is
25 conceptualised by people living with dementia and care partners.(10, 11)
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28 Qualitative studies of outcomes valued people living with dementia have been synthesised in two
29 recent reviews.(13, 14) However, our initial searches identified several relevant papers that were not
30 included. Further, we have not found parallel syntheses of the views of care partners on outcomes
31 desired for themselves or for the person with dementia they support. If possible, we will also include
32 papers reporting on the outcomes that people with dementia identify as important for their care
33 partner.
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36 The aim of this qualitative synthesis is to add to the existing literature by systematically searching for
37 papers exploring the related concepts of outcomes, well-being and quality of life. This will ensure
38 that as many relevant papers are included as possible and enable us to synthesise a broad range of
39 studies. We will also include papers on the lived experience of dementia since these are likely to
40 include relevant data which have not been included in previously reviews. Finally, we will add to the
41 existing literature by including the views of their care partners. Since people living with severe
42 dementia may not be able to express their views on key outcomes, the inclusion of care partners'
43 perspectives will facilitate consideration of outcomes throughout the whole of the illness trajectory.
44 Further, it will allow a unique comparison of the outcomes valued by people living with dementia
45 and their care partners, for themselves and for each other.
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50 Methods and analysis

51 Protocol and registration

52 The protocol is registered with PROSPERO [number anonymised] and is reported in line with the
53 Preferred Reporting Items for Systematic Review and Meta-Analyses Protocols (online
54 supplementary file 1).(15)
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REVIEW METHODS

Search strategy

We identified three domains of interest relating to the research question: type of study, participants and the phenomena of interest - outcomes or lived experience. For each domain we identified relevant keywords or search terms drawing on published search strategies with the addition of search terms, keywords and text words in the titles and abstracts of papers identified in pilot searches. An information specialist reviewed the proposed search terms. The search terms were used to develop tailored search strategies for each information source (see Appendix 1 for the Medline search). Since not all databases will be able to accommodate the full set of search terms, the strategy will be modified as appropriate. Details of the specific search terms used for each information source will be recorded.(16)

- Types of study

We will focus on studies reporting original qualitative data. Publications have explored the relative merits of different approaches to identifying qualitative research in different databases (17-22). We will use the University of Texas School of Public Health (23) search for qualitative research, which was reported to have the best balance between sensitivity and precision.(17) To increase the accuracy of this strategy, we modified the search after examining known papers in the specific field of interest.

- Participants

Studies must include people living with dementia and/or their care partners. Although there are established search strategies for dementia (e.g. those used to update evidence for the recent guidelines by the National Institute for Health and Care Excellence in England (24)) these were not considered appropriate for identifying qualitative studies. Instead, we will use a less complex strategy informed by terms used in previous reviews, supplementing the term 'dementia' with specific subtypes where these did not necessarily contain the word 'dementia' (e.g. Lewy body disease).

Separate search terms have not been included relating to care partners, since relevant papers will be captured within the broader search.

- Phenomena of interest

We will identify papers describing the outcomes valued by people living with dementia or their care partners. We will use a broad range of search terms to capture papers exploring related concepts such as well-being and quality of life. Similarly, while papers describing lived experience may not explicitly discuss outcomes, they may provide significant insights into areas of life that have particular salience or value to people living with dementia and care partners.

Data sources

Previous studies have recommended using a range of approaches to identify relevant information;(25, 26) sources to be used in the present study are summarised in Table 1.

Table 1: Data sources

Approach	Specific sources
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Electronic databases of academic articles (27)	MEDLINE, CINAHL, PsycInfo Social Sciences Premium Collection (including IBSS: and ASSIA)
Internet search engines (16, 26)	Google Scholar
Citation pearl growing	Review of references & citations of included studies Related article searching Citation alerts Publications of authors of included studies
Consultation with subject experts	Email requests to experts in the field
Databases of grey literature (25, 26, 28)	OpenGrey – system for information on grey literature in Europe British Library Catalogue – for books, book chapters and theses
Targeted websites of funders and third sector organisations (24)	Informed by the list of organisations included in grey literature searches by NICE (24) (see Appendix 2)

We will adopt the following definition of grey literature: ‘the diverse and heterogeneous body of material available outside, and not subject to, traditional academic peer-review processes’.(28) We will focus on first tier grey literature (which has significant retrievability/credibility and typically includes books, book chapters, government reports, and think tank publications).(28) Since there is no ‘gold standard’ for searching the grey literature,(29) we have drawn on accounts of grey literature searching in published qualitative syntheses to identify the most appropriate sources for this review.(16, 25, 26, 29) We started by considering the types of grey literature we wished to identify, then the sources from which these were likely to be retrieved. UK think tanks were identified by Google searches and then rapidly reviewed to ascertain their potential relevance to our work. A detailed description of sources to be included in the grey literature search is provided in Appendix 2.

DATA COLLECTION AND ANALYSIS

Selection of the studies

Details of the inclusion and exclusion criteria are provided in Table 2.

Table 2: Inclusion and exclusion criteria

Criteria	Justification
Conducted between 1990 and 2020	The earliest relevant paper identified in previous reviews was in 1992; we therefore propose to cover the last 30 years to ensure that we include all relevant publications.
Reports perspectives of people living with dementia or care partners	Participants are either people living with dementia (all subtypes) or their care partners. Evidence of formal diagnosis is not required for inclusion. We are using the term care partners to include unpaid informal carers/caregivers (this include family members and friends who are in receipt of direct payments and allowances)

<p>1 2 3 4 5 6 7 8 9 10 11 12</p> <p>Reports outcomes valued by people with dementia or care partners</p>	<p>Studies should explore the views of people with dementia on outcomes valued for themselves (or their care partners) or the lived experience of dementia. Alternatively, studies could explore the views of carer partners on outcomes valued for themselves (or the person whom they support) or the lived experience of caring for someone with dementia.</p> <p>Studies examining outcome measures will only be included where they report qualitative data on the views of person living with dementia or care partners to inform development.</p>
<p>13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29</p> <p>Original qualitative data</p>	<p>We will include all designs providing data on the voices of people with dementia and care partners (interviews, focus groups, case studies, secondary analysis, auto-ethnographies and observation <i>if the latter includes fieldnotes directly reporting the perspectives of people with dementia or care partners</i>). We will exclude (auto)biographies.</p> <p>Studies using survey data without open-ended questions or exploring responses to pre-populated lists of outcomes will be excluded. Studies using surveys with open-ended questions will be included if there is enough qualitative data to be reanalysed. Qualitative data from studies using mixed methods will be eligible for inclusion.</p> <p>Reviews, study protocols and editorials will not be eligible for inclusion. We will keep a record of relevant publications to check that related papers have been included where appropriate.</p>
<p>30 31 32 33 34 35</p> <p>Published in the English language</p>	<p>Resources are not available to include studies published in languages other than English. Since excluding papers not written in English may introduce a language bias, we will follow the recommendations of the Joanna Briggs Institute(30) to search inclusively and keep a record of the number of potentially relevant excluded studies by language.</p>

Selection process

Titles and abstracts of all papers identified through searching will be reviewed by one researcher. Previous authors have highlighted inconsistencies between reviewers during screening.(31) To develop a collective understanding of how to operationalise the screening criteria, all researchers will screen a sample of 10 papers independently then compare and discuss decisions. This will enable areas of ambiguity to be identified and resolved. This process will be repeated iteratively until the review team is confident in applying the criteria. Regular screening meetings will be held to discuss uncertainties and further clarify screening criteria as needed. Any papers where a decision cannot be reached by discussion will be included for full text review.

All full text papers retrieved will be reviewed by two researchers. A similar process of comparing screening decisions on samples of full text papers will be used to maximise consistency in applying the screening criteria. Ongoing meetings of the review team will review any disagreements regarding eligibility. If necessary, study authors will be contacted for further information; if a response is not received within one month, the article may be excluded if essential data are missing.

Data extraction and management

Rayyan QCRI software will be used to manage the screening processes and NVivo software will be used to manage data extraction and analysis. Data extraction will include study methodology, types of setting, number and types of participants, issues examined, country, date of data collection, and variables relating to quality appraisal.

NVivo 12 software will be used to facilitate data extraction. Drawing on work by Houghton, Murphy (32) each included paper will be assigned to a case and attributes used to record key information. In accordance with the thematic synthesis method, full results or findings sections will be extracted and stored within the NVivo software.

Assessment of quality of included studies

There is a lack of consensus about quality assessment in qualitative systematic reviews, and many different tools and techniques are now available. Following detailed review of published approaches (30, 31, 33-36) we identified the developed by Croucher (2003) as most appropriate to our review.(37) We will also follow the recommendation to tailor the approach to this particular review.(38) We will include items on:

- The quality of reporting
- Adequacy of strategies to establish the validity of the findings
- Appropriateness of the methods to ensure that the findings were rooted in the perspectives of participants.

Studies will not be excluded on the basis of quality, but quality appraisal will be used to assess confidence in the review findings.

DATA SYNTHESIS AND ANALYSIS

The findings or results sections of included papers will form the data for the synthesis. The three-stage approach described by Thomas and Harden (33) will be followed: line by line coding; identification of descriptive themes; and development of conceptual themes. Reported findings will therefore not be taken at face value but will be subject to a process of scrutiny and reconceptualization.

At each stage, emerging codes and concepts will be discussed in data workshops involving all available reviewers. Narrative summaries of each descriptive code will be produced by researchers and discussed in further data workshops to identify emerging conceptual themes. We will compare the outcomes identified by people with dementia for themselves with those identified by care partners for people with dementia and *vice versa*.

Assessment of confidence in the review findings

We will use the GRADE CERQual approach to assess confidence in the review findings.(39) This involves an assessment of each individual review finding in relation to the following four areas:

- Methodological limitations (the extent to which there are concerns about the design or conduct of the primary studies that contributed evidence to an individual review finding)
- Coherence (an assessment of how clear, well supported or compelling the fit is between the data from the primary studies and a review finding that synthesises the original data)

- Adequacy of data (an overall determination of the degree of richness and quantity of data supporting a review finding)
- Relevance (the extent to which the body of evidence from the primary studies supporting a review finding is applicable to the context, perspective or population)

This information will be presented in a Summary of Qualitative Findings (SoQF) table.(40)

Patient and Public Involvement

A mixed stakeholder involvement group, comprising people living with dementia, current and former care partners and professionals working with these groups, has informed the design of this review, and will contribute to the interpretation of the review findings. The [PPI group name anonymised] was established in 2018 to ensure stakeholder involvement is embedded throughout the conduct and dissemination of our research programme.

The [PPI group name anonymised] has shaped the design of this review in two ways; firstly by highlighting that a wide range of outcomes need to be considered since their relative importance is determined by personal preferences, circumstances and point along the illness trajectory; and secondly by emphasising the need to consider outcomes for care partners, as well as those for people living with dementia. The [PPI group name anonymised] will also contribute to identifying conclusions from the results of the review and identify appropriate dissemination routes for non-academic audiences.

Ethics and dissemination

Research ethics approval and consent to participate is not required for this review. We will draw on guidelines for the publication of qualitative synthesis in reporting the findings.(41) The findings will be made accessible to health and care professionals, policy and decision-makers, and the public. The results will be disseminated at regional, national and international conferences.

Authors' contributions

[Anonymised] and [Anonymised] drafted the protocol. [Anonymised], [Anonymised], and [Anonymised] conceived the initial study idea and [Anonymised], [Anonymised] and [Anonymised] completed preliminary work to inform its development. All authors made substantial contributions to the design of the study, revised the manuscript critically for important intellectual content, and approved the final manuscript. [Anonymised] is the guarantor of the review.

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Competing interests statement

[Anonymised] reports grants from [Anonymised], outside the submitted work.

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Appendix 1: search strategy for Medline

1 AND 2 AND (3 OR 4)*

1. Methodology:

((("semi-structured" OR semistructured OR unstructured OR informal OR indepth OR "in-depth" OR "face-to-face" OR structured or guide) adj3 (interview* OR discussion* OR questionnaire*))).ti,ab. OR ("focus group*" OR qualitative OR ethnograph* OR fieldwork OR "field work" OR "key informant" OR "grounded theory" OR "phenomenol*" OR narrative).ti,ab. OR "interviews as topic"/ OR "focus groups"/ OR narration/ OR "qualitative research"/

2. Dementia:

Dement* OR Alzheimer* OR Lewy* OR FTD OR "Frontotemporal degenerat*" OR "Frontotemporal disorder*" OR "frontal temporal degenerat*" or "frontal temporal disorder**"

3. Outcomes:

Need* OR Want* OR Demand* OR Domain* OR Importan* OR Wellbeing OR "Well-being" OR "well being" OR "Quality of life" OR "QoL" OR Prefer* OR Satisf* OR impact* OR View* OR Outcome* OR Hope* OR coping OR cope* OR Expect*

4. Lived Experience:

Experience* OR Meaning* OR Perception* OR Perceiv* OR Understand* OR subjectiv* OR "Everyday li*" OR "every day li*" OR "every-day li*" OR "day-to-day li*" OR "day to day li*" OR "daily li*" OR Narrative* OR Perspective* OR Scheme* OR Exist* OR Representation* OR Value* OR Belief* OR Identit* OR Self* OR selves

*Planned limits included narrowing data search to studies conducted between 1990 and 2020, and including 'In-Process & Other Non-Indexed Citations' from Medline.

Appendix 2: sources of grey literature to be included

Type of grey literature	Source type	Sources
Dementia strategies & guidelines (international)	Websites	alz.co.uk alzheimer-europe.org nice.org.uk scie.org.uk alzheimer.ca alz.org dementia.org.au
Theses, book chapters, conference proceedings, abstracts and conference papers (international)	Database search	British Library Catalogue (bl.uk)
Organisations of and for people living with dementia and carers (UK)	Websites	alzheimers.org.uk dementiauk.org youngdementia.uk.org lewybody.org raredementiasupport.org dementiavoices.org.uk Mentalhealth.org.uk Carersuk.org
Organisations of and for people living with dementia (international)	Websites	alz.co.uk alzheimer-europe.org dementiaallianceinternational.org
UK policy and consultations	Websites	gov.uk gov.scot gov.wales northernireland.gov.uk
UK regulators	Websites	Care Quality Commission
UK think tanks focusing on domestic policy	Websites Reports	Centre for Health & the Public Interest Demos Health Foundation Institute for Public Policy Research Involve Joseph Rowntree Foundation The Kings Fund National Centre for Social Research Nesta New Local Government Network Nuffield Council on Bioethics

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		Nuffield Trust ResPublica (<i>Care after Cure</i>) Social Market Foundation Wales Institute of Social & Economic Research, Data and Methods (<i>Living well with dementia</i>) The Work Foundation (<i>carers</i>)
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Outcomes valued by people living with dementia and their care partners: Protocol for a qualitative systematic review and synthesis

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Outcomes valued by people living with dementia and their care partners: Protocol for a qualitative systematic review and synthesis

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Abstract

Introduction: Growing numbers of interventions are being developed to support people and families living with dementia, but the extent to which they address the areas of most importance to the intended recipients is unclear. This qualitative review will synthesise outcomes identified as important from the perspectives of people living with dementia and their care partners, both for themselves and each other.

Methods and analysis: The review will employ thematic synthesis methodology. Studies from 1990 or later will be eligible if they include qualitative data on the views of people living with dementia or their care partners on valued outcomes or the lived experience of dementia. Databases to be searched include MEDLINE, CINAHL, PsycInfo and Social Sciences Premium Collection, in addition to systematically gathered grey literature. Rayyan QCRI software will be used to manage the screening processes and NVivo software will be used to manage data extraction and analysis. The review will also critically evaluate the extent to which international recommendations address the areas of importance to people living with dementia and their families. The findings will be of relevance to researchers, policy makers, and providers and commissioners of dementia services. The protocol is written in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols guidelines.

Ethics and dissemination: As the methodology of this study consists of collecting data from publicly available articles, it does not require ethical approval. We will share the results through conference presentations and an open access publication in a peer-reviewed journal. Our mixed stakeholder involvement group will advise on dissemination to non-academic audiences.

Systematic review registration: PROSPERO CRD42020219274

Strengths and limitations of this study

- We will focus on outcomes articulated by people living with dementia and care partners using qualitative methodologies
- We will include studies of the lived experience of dementia which are likely to highlight important outcomes but have not been included in previous reviews
- Outcomes valued by people living with dementia and care partners will be explored and compared.
- The perspectives of people living with dementia and their care partners have informed our study design and will contribute to data interpretation and dissemination through lay involvement
- Studies not published in English will not be included in this review but will be labelled and recorded.

Keywords: Dementia, Qualitative Research, Systematic Review, Outcomes, Quality of Life, thematic synthesis, qualitative synthesis

Introduction

International policy is undergoing a shift in focus from improving diagnostic rates of dementia to enhancing post-diagnostic support, reflected in an emphasis on enabling people to 'live well' with dementia(1-7) or to live a life with meaning and dignity.(8) To achieve these emerging policy aims, we need to understand what these abstract concepts, along with similar concepts such as 'needs', 'quality of life' or 'wellbeing', mean to people living with dementia and their care partners, caregivers or carers (hereafter care partners) in order to translate them into specific outcomes which can be used to inform and evaluate post-diagnostic support. It is essential to people living with dementia and their care partners in this process of translation to ensure that interventions focus on the outcomes valued by the intended beneficiaries,(9) as highlighted in the OECD call for health systems to 'measure what matters'.(10)

The term 'outcome' may be used in different ways. The NHS Good Indicators Guide defines outcomes as 'a measurable change in health status, sometimes attributable to a risk factor or an intervention'.(11) This definition is strongly focused on changes in health, which can be problematic when applied a condition such as dementia that also has substantial emotional and social components;(12) Coulter(10) has argued that outcomes for people living with long term conditions, such as dementia, should encompass a broad view of health and wellbeing, rather than focusing on physical functioning. Nocon and Qureshi(13) have defined outcomes more broadly as 'the impact, effect or consequence of a service or a policy for service users', while Harding et al(14) have defined outcomes as 'impact of activity or support and services'. In this review, we are using an amalgamated definition: 'the impact, effect or consequence of activity, support, services or policy for people living with dementia and/or their care partners'. By adopting this broad definition we hope to identify outcomes that may have otherwise been missed.

Recent research into outcomes prioritised by people living with dementia and care partners, has focused on developing core outcome sets for intervention studies. To date, core outcome sets have been developed for disease modification trials,(15) psychosocial interventions,(16) physical activity,(17) medication management,(18) and nonpharmacological community-based health and social care interventions.(19) Such core outcome sets developed for use in specific contexts may have limited utility when evaluating the impact of interventions, services and national policy which may have broader aims and seek to address multiple areas. Furthermore, the extent to which the views of people living with dementia have been included in these studies varies, although some have developed innovative methods to capture their perspectives.(18, 19) This has sometimes highlighted discrepancies between outcomes valued by people living with dementia and those valued by professionals.(17, 18)

A recent systematic review sought to address the above limitations by focusing on outcomes important to all key stakeholder groups: people living with dementia, their care partners and health care professionals. It described 32 outcomes grouped into categories of clinical, practical and personal.(20) However, the study focused only on Alzheimer's disease and mild cognitive impairment.(20) A review of qualitative and mixed methods studies found a very wide range of needs of people living with dementia and care partners including physical and mental health, social activities, information provision and financial assistance.(21) However, some studies in the review relied on pre-specified lists of needs;(21) all needs may therefore not have been captured. Recent systematic reviews focusing on outcomes for carers(22, 23), including children of parents with young onset dementia,(24) have been conducted. However, these studies were limited in scope as they did not incorporate grey literature. Other issues include not exploring the relationship between needs

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3 for the care partner and needs for the person with dementia;(23) a systematic review on mutual
4 support between patients and care partners(25) did not incorporate any studies about dementia,
5 suggesting this is an under-researched area. Moreover, we identified a conceptual muddle around
6 interpreting outcomes that people living with dementia/care partners value for themselves versus
7 outcomes they value for the other person.(20-22) In addition, the majority of studies included in
8 recent reviews of outcomes(20-24) and lived experience(26-30) have been from higher income
9 countries; there is therefore a need to explore the views of people living with dementia and their
10 care partners in lower-middle income countries as these may differ.
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13 In order to comprehensively describe outcomes valued by people living with dementia and their care
14 partners, this qualitative synthesis aims to build upon existing literature by systematically reviewing
15 relevant databases (research, grey literature and policy) for papers exploring the related concepts of
16 outcomes, needs, wellbeing and quality of life. Papers on the lived experience of dementia will also
17 be incorporated as, while previous reviews have explored lived experience separately(26-29) and
18 incorporated it into measures of wellbeing,(31) these have not previously been used to inform
19 outcomes. As articulating outcomes can be challenging, particularly if there is a focus on outcomes
20 of specific services, where people living with dementia and care partners may have low expectations
21 or be unaware of the wider range of outcomes that could be achieved from a comprehensive
22 package of support, we believe these will shed additional light on valued aspects of life which may
23 otherwise be missed. Finally, we will add to the existing literature by explicitly exploring the
24 outcomes valued by people living with dementia for their care partners and vice versa in addition to
25 the outcomes that each value for themselves; in previous syntheses, these four strands have
26 frequently not been separated adequately.
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33 Methods and analysis

34 Protocol and registration

35 The protocol is registered with PROSPERO [CRD42020219274] and is reported in line with the
36 Preferred Reporting Items for Systematic Review and Meta-Analyses Protocols (online
37 supplementary file 1).(32)
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42 Review methods

43 *Search strategy*

44 We identified three domains of interest relating to the research question: type of study;
45 participants; and the phenomena of interest (i.e. outcomes or lived experience). For each domain we
46 identified relevant keywords or search terms, drawing on published search strategies with the
47 addition of search terms, keywords and text words in the titles and abstracts of papers identified in
48 pilot searches (see table 1). The search terms were used to develop tailored search strategies for
49 each information source (see Appendix 1 for the Medline search); an information specialist reviewed
50 the proposed search terms. Since not all databases will be able to accommodate the full set of
51 search terms, the strategy will be modified as appropriate. Details of the specific search terms used
52 for each information source will be recorded.
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58 Table 1: Terms and synonyms used to inform the search

59 Group	60 Terms
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1	Qualitative methodology	Interview Focus group Fieldwork Discussion	Ethnography Questionnaire Qualitative	Phenomenological Grounded theory Narrative
2	Dementia	Dementia Lewy Body disease	Alzheimer's disease Frontotemporal degeneration	Frontotemporal disorder
3	Outcomes	Need Want Demand Domain Important	Wellbeing Quality of life Prefer Satisfaction Impact	View Outcome Hope Cope/coping Expect
4	Lived experience	Experience Meaning Perception Understanding Subjective	Everyday/daily life Narrative Perspective Scheme Existence	Representation Value Belief Identity Self

- Types of study

We will focus on studies reporting original qualitative data since our focus is on outcomes articulated by people living with dementia and care partners. Publications have explored the relative merits of different approaches to identifying qualitative research in different databases.(33-38) We will use the University of Texas School of Public Health(39) search for qualitative research, which was reported to have the best balance between sensitivity and precision. To increase the accuracy of this strategy, we modified the search after examining known papers in the specific field of interest, adding terms for 'phenomenology', 'grounded theory' and 'narrative'.

- Participants

Studies must include people living with dementia and/or their care partners. Although there are established search strategies for dementia (e.g. those used to update evidence for the recent guidelines by the National Institute for Health and Care Excellence (NICE) in England) these were not considered appropriate for identifying qualitative studies. Instead, we will use a less complex strategy informed by terms used in previous reviews, supplementing the term 'dementia' with specific subtypes where these did not necessarily contain the word 'dementia' (e.g. Lewy body disease). We will be more inclusive than previous reviews by not specifying place of residence or including terms relating specifically to service use.(21)

Specific search terms relating to care partners have not been included, as papers focusing on care partners for people with dementia are a subset of papers about dementia and will be retrieved by our existing search. Adding such terms would have additionally required us to operationalise the term 'care partners' to ensure that all relevant papers were included; this was an issue in previous reviews which used a limited range of terms for care partners.(20, 21)

- Phenomena of interest

We will identify papers describing the outcomes valued by people living with dementia or their care partners. We will use a broad range of search terms to capture papers exploring related concepts such as wellbeing and quality of life (see table 1); these terms were developed through iterative team discussions, previous reviews,(20, 21) and examination of known papers of interest to ensure

they were comprehensive. Additionally, papers describing lived experience of dementia may provide significant insights into areas of life that have particular salience or value to people living with dementia and care partners; we will therefore also include a range of terms relating to lived experience (see table 1), developed through a similar iterative process consulting previous reviews.(26-29) Relevant studies need only describe either outcomes or lived experience, not both. Previous reviews have limited potential results by including a complex combination of search terms, for example the requirement to include ‘priorities’(20) or terms relating to evaluation;(21) in keeping with our broad definition of outcomes, we have used a more streamlined search strategy.

Data sources

Previous studies have recommended using a range of approaches to identify relevant information;(40, 41) sources to be used in the present study are summarised in Table 2.

Table 2: Data sources

Approach	Specific sources
Electronic databases of academic articles (34)	MEDLINE, CINAHL, PsycInfo Social Sciences Premium Collection (including IBSS and ASSIA)
Internet search engines (41, 42)	Google Scholar
Citation pearl growing	Review of references & citations of included studies Related article searching Citation alerts Publications of authors of included studies
Databases of grey literature (40, 41, 43)	OpenGrey British Library Catalogue
Targeted websites of funders and third sector organisations (44)	Informed by the list of organisations included in grey literature searches by NICE (44) (see Appendix 2)

We will adopt the following definition of grey literature: ‘the diverse and heterogeneous body of material available outside, and not subject to, traditional academic peer-review processes’. We will focus on first tier grey literature (which has significant retrievability/credibility and typically includes books, book chapters, government reports, and ‘think tank’ publications).(43) Since there is no ‘gold standard’ for searching the grey literature,(45) we have drawn on accounts of grey literature searching in published qualitative syntheses to identify the most appropriate sources for this review.(40-42, 45) We started by considering the types of grey literature we wished to identify, then the sources from which these were likely to be retrieved, including international policy documents and reports by organisations for people living with dementia. UK think tanks were identified by Google searches and then rapidly reviewed to ascertain their potential relevance to our work. A detailed description of sources to be included in the grey literature search is provided in Appendix 2.

Data collection and analysis

Selection of the studies

Details of the inclusion and exclusion criteria are provided in Table 3.

Table 3: Inclusion and exclusion criteria

Criteria	Justification
Conducted between 1990 and 2020	The earliest relevant paper identified in previous reviews was in 1992; we therefore propose to cover the last 30 years to ensure that we include all relevant publications.
Reports perspectives of people living with dementia or care partners	Participants are either people living with dementia (all subtypes) or their care partners. Evidence of formal diagnosis is not required for inclusion. We are using the term 'care partners' to mean family members, friends or neighbours who are typically unpaid (although we will include those in receipt of direct payments and allowances)
Reports outcomes valued by people with dementia or care partners	<p>Studies should explore the views of people with dementia on outcomes valued for themselves (or their care partners) or the lived experience of dementia. Alternatively or additionally, studies could explore the views of care partners on outcomes valued for themselves (or the person whom they support) or the lived experience of caring for someone with dementia.</p> <p>Studies examining outcome measures will only be included where they report qualitative data on the views of people living with dementia or care partners to inform development.</p>
Original qualitative data	<p>We will include all designs providing data on the voices of people with dementia and care partners (interviews, focus groups, case studies, secondary analysis, auto-ethnographies and observation <i>if the latter includes fieldnotes directly reporting the perspectives of people with dementia or care partners</i>). We will exclude (auto)biographies.</p> <p>Studies using survey data without open-ended questions or exploring responses to pre-populated lists of outcomes will be excluded. Studies using surveys with open-ended questions will be included if there is enough qualitative data to be reanalysed. Qualitative data from studies using mixed methods will be eligible for inclusion.</p> <p>Reviews, study protocols and editorials will not be eligible for inclusion. We will keep a record of relevant publications to check that related papers have been included where appropriate.</p>
Published in the English language	Resources are not available to include studies published in languages other than English. Since excluding papers not written in English may introduce a language bias, we will follow the recommendations of the Joanna Briggs Institute to search inclusively and keep a record of the number of potentially relevant excluded studies by language.

Selection process

Titles and abstracts of all papers identified through searching will be reviewed by one researcher. Previous authors have highlighted inconsistencies between reviewers during screening. To develop a

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3 collective understanding of how to operationalise the screening criteria, all researchers will screen a
4 sample of 10 papers independently then compare and discuss decisions. This will enable areas of
5 ambiguity to be identified and resolved. This process will be repeated iteratively until the review
6 team is confident in applying the criteria. Regular screening meetings will be held to discuss
7 uncertainties and further clarify screening criteria as needed. Any papers where a decision cannot be
8 reached by discussion will be included for full text review.
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11 A similar process of comparing screening decisions on samples of full text papers will be used to
12 maximise consistency in applying the screening criteria. A proportion of full text papers retrieved will
13 be reviewed by two researchers. Ongoing meetings of the review team will discuss and resolve any
14 disagreements regarding eligibility. If necessary, study authors will be contacted for further
15 information; if a response is not received within one month, the article may be excluded if essential
16 data are missing.
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21 Data extraction and management

22 EndNote software will be used for data management and deduplication, in combination with Rayyan
23 QCRI software(46) to facilitate the screening process.
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26 NVivo 12 software will be used to assist data extraction and analysis. Drawing on work by Houghton
27 and Murphy,(47) each included paper will be assigned to a case and attributes used to record key
28 information. In accordance with the thematic synthesis method, full results or findings sections will
29 be extracted and stored within the NVivo software. Additional data extracted will include study
30 methodology, country, setting, number and types of participants, whether the paper explicitly
31 explored outcomes or focused on lived experience, date of data collection, and variables relating to
32 quality appraisal.
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35 Assessment of quality of included studies

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37 There is a lack of consensus about quality assessment in qualitative systematic reviews, and many
38 different tools and techniques are available.(48) Following the approach to qualitative synthesis
39 developed by Thomas and Harden(49, 50), we intended to adapt quality appraisal criteria to our
40 specific review. We examined several methods for quality assessment,(49, 51-56) mapping headings
41 across tools, and tested them on a small batch of papers; this identified some elements that were
42 less relevant to our review (e.g. they were not reported in the papers of interest) and others that
43 were difficult to operationalize. Based on this exercise, we selected Croucher(56) as a base tool, due
44 to its ease of operationalisation, coverage of the key quality issues of relevant to our review and few
45 superfluous items, and modified it accordingly. We will include items on:
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- 48 - Appropriateness of the methods to ensure that the findings were rooted in the perspectives
49 of participants
- 50 - Adequacy of strategies to establish the validity of the findings
- 51 - The quality of reporting.
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54 Studies will not be excluded on the basis of quality, but quality appraisal will be used to assess
55 confidence in the review findings.
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Data synthesis and analysis

The findings or results sections of included papers will form the data for the synthesis. The three-stage thematic synthesis approach described by will be followed: line by line coding; identification of descriptive themes; and development of conceptual themes. We will also draw on the thematic approach described by Braun and Clarke (57) for the process of familiarisation with the data and generation of initial codes. Reported findings and interpretation will not be taken at face value but will be subject to a process of scrutiny and reconceptualization, particularly those relating to lived experiences, as the extent to which outcomes are explicitly articulated will vary between papers. Lived experience data will be interpreted through an outcomes 'lens', for example looking for terminology that can be interpreted as expressing a desired outcome (e.g. 'want', 'need', 'wish') or identifying an element of post-diagnostic support that is missing; at this stage, our aim will be to stick closely to the terms used by participants and avoid imposing concepts on the data. Initial codes will be discussed in data workshops to produce a preliminary list of potential outcomes. This process will continue iteratively until the dataset has been analysed.

At each stage, emerging codes and concepts will be discussed in data workshops involving all available reviewers. Narrative summaries of each descriptive code will be produced by researchers and discussed in further data workshops to identify emerging conceptual themes. We will compare the outcomes identified by:

- people living with dementia for themselves;
- care partners for people living with dementia;
- people living with dementia for their care partners;
- and care partners for themselves.

Assessment of confidence in the review findings

We will use the GRADE CERQual approach to reflexively assess confidence in the review findings.(58) This involves an assessment of each individual review finding in relation to the following four areas:

- Methodological limitations (the extent to which there are concerns about the design or conduct of the primary studies that contributed evidence to an individual review finding)
- Coherence (an assessment of how clear, well supported or compelling the fit is between the data from the primary studies and a review finding that synthesises the original data)
- Adequacy of data (an overall determination of the degree of richness and quantity of data supporting a review finding)
- Relevance (the extent to which the body of evidence from the primary studies supporting a review finding is applicable to the context, perspective or population)

Reflexivity about the context of knowledge production and the effect of the researchers is central to good qualitative research, including evidence synthesis.(59) Using the CERQUAL approach will enable us to be explicit about how and why judgements about individual review findings have been made, and to check for consistency across and between different types of papers (outcomes and lived experience). Furthermore, examining each review finding in detail allows a more nuanced assessment than a global statement about the confidence in the findings. This information will be presented in a Summary of Qualitative Findings (SoQF) table.(60)

Patient and Public Involvement

A mixed stakeholder involvement group, comprising people living with dementia, current and former care partners and professionals working with these groups, has informed the design of this review, and will contribute to the interpretation of the review findings. The Dementia Care Community (DCC) was established in 2018 to ensure stakeholder involvement is embedded throughout the conduct and dissemination of our research programme.

The DCC has shaped the design of this review in two ways; firstly by highlighting that a wide range of outcomes need to be considered since their relative importance is determined by personal preferences, circumstances and point along the illness trajectory; and secondly by emphasising the need to consider outcomes for care partners, as well as those for people living with dementia. The DCC will also contribute to identifying conclusions from the results of the review and identify appropriate dissemination routes for non-academic audiences.

Ethics and dissemination

Research ethics approval and consent to participate is not required for this review. We will draw on guidelines for the publication of qualitative synthesis in reporting the findings. The findings will be made accessible to health and care professionals, policy and decision-makers, and the public. The results will be disseminated at regional, national and international conferences.

Authors' contributions

Contributor LR is the guarantor of the review. CB, LR, and AW conceived the initial study idea and AW, CB and GB completed preliminary work to inform its development. LB, CB, GB, LR and AW drafted the manuscript. All authors (LB, CB, GB, SB, JM, LR and AW) made substantial contributions to the design of the study, revised the manuscript critically for important intellectual content, and approved the final manuscript.

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Competing interests statement

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Appendix 1: search strategy for Medline

	Searches
1	((("semi-structured" or semistructured or unstructured or informal or indepth or "in-depth" or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire*)) or ("focus group*" or qualitative or ethnograph* or fieldwork or "field work" or "key informant" or "grounded theory" or "phenomenol*" or narrative)).ti,ab. or "interviews as topic"/ or "focus groups"/ or narration/ or "qualitative research"/
2	(Dement* or Alzheimer* or Lewy* or FTD or "Frontotemporal degenerat*" or "Frontotemporal disorder*" or "frontal temporal degenerat*" or "frontal temporal disorder*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
3	(Need* or Want* or Demand* or Domain* or Importan* or Wellbeing or "Well-being" or "well being" or "Quality of life" or "QoL" or Prefer* or Satisf* or impact* or View* or Outcome* or Hope* or coping or cope* or Expect*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
4	(Experience* or Meaning* or Perception* or Perceiv* or Understand* or subjectiv* or "Everyday li*" or "every day li*" or "every-day li*" or "day-to-day li*" or "day to day li*" or "daily li*" or Narrative* or Perspective* or Scheme* or Exist* or Representation* or Value* or Belief* or Identit* or Self* or selves).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
5	3 or 4
6	1 and 2 and 5

*Planned limits included narrowing data search to studies conducted between 1990 and 2020, and including 'In-Process & Other Non-Indexed Citations' from Medline.

Appendix 2: sources of grey literature to be included

Type of grey literature	Source type	Sources
Dementia strategies & guidelines (international)	Websites	alz.co.uk alzheimer-europe.org nice.org.uk scie.org.uk alzheimer.ca alz.org dementia.org.au
Theses, book chapters, conference proceedings, abstracts and conference papers (international)	Database search	British Library Catalogue (bl.uk)
Organisations of and for people living with dementia and care partners (UK)	Websites	alzheimers.org.uk dementiauk.org youngdementia.uk.org lewybody.org raredementiasupport.org dementiavoices.org.uk Mentalhealth.org.uk Carersuk.org
Organisations of and for people living with dementia (international)	Websites	alz.co.uk alzheimer-europe.org dementiaallianceinternational.org
UK policy and consultations	Websites	gov.uk gov.scot gov.wales northernireland.gov.uk
UK regulators	Websites	Care Quality Commission
UK think tanks focusing on domestic policy	Websites Reports	Centre for Health & the Public Interest Demos Health Foundation Institute for Public Policy Research Involve Joseph Rowntree Foundation The Kings Fund National Centre for Social Research Nesta New Local Government Network Nuffield Council on Bioethics Nuffield Trust

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		ResPublica (<i>Care after Cure</i>) Social Market Foundation Wales Institute of Social & Economic Research, Data and Methods (<i>Living well with dementia</i>) The Work Foundation (<i>care partners</i>)
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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		Page and 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"/>	P3
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"/>	P2
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"/>	P1
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	<input checked="" type="checkbox"/>	<input type="checkbox"/>	10
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"/>	P10
Sponsor	5b	Provide name for the review funder and/or sponsor	<input checked="" type="checkbox"/>	<input type="checkbox"/>	P10
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"/>	P10
INTRODUCTION					
Rationale	6	Describe the rationale for the review in the context of what is already known	<input checked="" type="checkbox"/>	<input type="checkbox"/>	P3
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"/>	P5

Section/topic	#	Checklist item	Information reported		Page and line number(s)
			Yes	No	
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"/>	P6-7
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"/>	P6
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 type="checkbox"/>	<input checked="" type="checkbox"/>	Appendix 1
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"/>	P8
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"/>	P8-9
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"/>	P8-9
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"/>	P6-7
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"/>	P6-7
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"/>	P6-7
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	<input checked="" type="checkbox"/>	<input type="checkbox"/>	P8-9
	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"/>	P8-9
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	<input checked="" type="checkbox"/>	<input type="checkbox"/>	P8-9

Section/topic	#	Checklist item	Information reported		Page and line number(s)
			Yes	No	
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"/>	
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"/>	P8-9

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