

National Institute for Health and Care Excellence

Draft for consultation

Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education

[E] Evidence review for palliative and end of life care

NICE guideline TBC

Evidence reviews

August 2021

Draft for consultation

These evidence reviews were developed by the National Guideline Alliance which is a part of the Royal College of Obstetricians and Gynaecologists

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1 Palliative and end of life care

2 Recommendations supported by this evidence review

3 This evidence review supports recommendations 1.9.1 – 1.9.9.

4 Review question

5 What combined health, social care and education service delivery arrangements can best
6 provide for the needs of disabled children and young people with severe complex needs on a
7 palliative or advance care plan, and for the needs of their families and carers?

8 Introduction

9 This review aims to determine the most effective combined health, social care and education
10 service delivery arrangements to meet the needs of disabled children and young people with
11 severe complex needs on a palliative or advance care plan and their families and carers.

12 At the time of scoping and developing the review protocols, documents referred to health,
13 social care and education in accordance with NICE style. When discussing the evidence and
14 making recommendations, these services will be referred to in the order of education, health
15 and social care for consistency with education, health and care plans.

16 Summary of the protocol

17 See Table 1 for a summary of the Population, Intervention, Comparison and Outcome
18 (PICO) characteristics of this review.

19 Table 1: Summary of the protocol (PICO table)

Population	<ul style="list-style-type: none">• Disabled children and young people from birth to 25 years with severe complex needs requiring health, social care and education support on a palliative or advance care plan• Families and carers of disabled children and young people from birth to 25 years with severe complex needs requiring health, social care and education support on a palliative or advance care plan
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Intervention	<p>Any commissioning, practice and service delivery models (approaches, configurations of resources and services) delivering 2 or more of health, social care and education services.</p> <p>For example:</p> <p>Practice and service delivery models</p> <ul style="list-style-type: none"> • Delivery arrangements: <ul style="list-style-type: none"> ○ Who provides care and how the healthcare workforce is managed: <ul style="list-style-type: none"> - Role-expansion/ task shifting ○ Coordination of care and management of care processes: <ul style="list-style-type: none"> - Individual case (service user) management (models responsive to individual needs) - Communication / referral between providers - Shared care - Shared decision making - Multidisciplinary teams - Multiagency assessment tool for service requirements (e.g. West Sussex tool) <p>Commissioning models:</p> <ul style="list-style-type: none"> • Delivery arrangements: <ul style="list-style-type: none"> ○ Coordination of care and management of care processes: <ul style="list-style-type: none"> - Integration (consolidation) of services • Financial arrangements: <ul style="list-style-type: none"> ○ Mechanisms for the payment of health services: <ul style="list-style-type: none"> - Joint/pooled budgets • Governance arrangements: <ul style="list-style-type: none"> ○ Authority and accountability for organisations: <ul style="list-style-type: none"> - Joint commissioning teams - Strategic oversight of commissioning
Comparison	<ul style="list-style-type: none"> • Any other joined-up commissioning, practice or service delivery models • Separate health, social and education services (without joined- up working or with some services not involved at all)
Outcome	<p>Critical</p> <ul style="list-style-type: none"> • Extent to which needs are met (including changing and evolving needs) <ul style="list-style-type: none"> ○ Health needs ○ Social care needs ○ Educational needs • Quality of life (both health- and social-related quality, and degenerative health versus function) <p>Important</p> <ul style="list-style-type: none"> • Social inclusion • Parallel planning/preparation for adulthood • Choice of place for end of life care • Satisfaction (child or young person and parent or carer) with palliative and/or advance care • Families stress and anxiety

1

2 For further details see the review protocol in appendix A.

1 Methods and processes

2 This evidence review was developed using the methods and process described in
3 [Developing NICE guidelines: the manual](#). Methods specific to this review question are
4 described in the review protocol in appendix A and the methods document (Supplement A).

5 Declarations of interest were recorded according to [NICE's conflicts of interest policy](#).

6 Effectiveness evidence

7 Included studies

8 Two before and after studies (Hays 2006 and Horrocks 2002) were included in this review.

9 The included studies are summarised in Table 2.

10 Both studies (Hays 2006 and Horrocks 2002) compared before and after the implementation
11 of services resulting in changes in aspects of coordination of care and management of care
12 processes.

13 See the literature search strategy in appendix B and study selection flow chart in appendix C.

14 Excluded studies

15 Studies not included in this review are listed, and reasons for their exclusion are provided in
16 appendix J.

17 Summary of studies included in the effectiveness evidence

18 Summaries of the studies that were included in this review are presented in Table 2.

19 **Table 2: Summary of included studies**

Study	Population	Intervention	Comparison	Outcomes	Comments
Hays 2006 Before and after study USA	Children and young people aged 0-21 years with a severe illness that may result in death within 2 years.	<u>After SPPCP (n=41)*</u> Curative and comfort family-centred palliative care service with 3 main components: 1) clinical-decision making (taking into account patient/family preference), 2) provider education and 3) flexible administration of benefits/co-case management. Project team included physicians, nurses, social worker, benefits coordinator and case managers from insurance plans.	<u>Before SPPCP (n=41)*</u> No information reported.	<ul style="list-style-type: none"> Quality of life Satisfaction with palliative and/or advance care 	<ul style="list-style-type: none"> Matched before and after data was only available for a maximum of n=22 depending on outcome Evidence for the population is indirect as children with cancer and cardiac disease (accounting for 39% of the sample) are unlikely to have severe complex needs in all three areas

Study	Population	Intervention	Comparison	Outcomes	Comments
Horrocks 2002 Before and after study UK	Children (with life-limiting genetic, metabolic and degenerative disorders) referred to the Avon Lifetime Service.	<u>After ALS (n=16)*</u> Community nursing and psychology service that included coordinating services and liaising with schools and social services. Aimed to reduce stress, improve wellbeing, support and educate families to care for their child, reduce hospital attendance, educate and train other carers, assist with networking to reduce isolation and enable children to receive care and die in an environment of their choice.	<u>Before ALS (n=16)</u> No information reported.	<ul style="list-style-type: none"> Extent to which needs are met 	Follow-up data was available for an additional 13 children but these data have not been extracted as no comparative data was available

1 ALS: Avon Lifetime Service, SPPCP: Seattle Pediatric Palliative Care Project

2 See the full evidence tables in appendix D. No meta-analysis was conducted (and so there
3 are no forest plots in appendix E).

4 Summary of the effectiveness evidence

5 There was evidence of an important benefit of the Seattle Pediatric Palliative Care Project in
6 terms of improving quality of life. There was potentially an important benefit of the Avon
7 Lifetime Service in terms of extent to which information needs are met and reduced
8 difficulties in nursing care, but there was uncertainty around the estimated effect. Further,
9 there were no important differences between before and after these interventions for other
10 domains of quality or life and satisfaction, and extent to which equipment and respite needs
11 were met, respectively.

12 Only two studies were found for this review question and the evidence was very low quality,
13 from single studies and seriously imprecise. Neither study reported social inclusion, parallel
14 planning/preparation for adulthood, choice of place for end of life care or families stress and
15 anxiety.

16 See appendix F for full GRADE tables.

17 Economic evidence

18 Included studies

19 A systematic review of the economic literature was conducted but no economic studies were
20 identified which were applicable to this review question.

21 A single economic search was undertaken for all topics included in the scope of this
22 guideline. See Supplement B for details.

1 Excluded studies

2 Economic studies not included in this review are listed, and reasons for their exclusion are
3 provided in appendix J.

4 Summary of included economic evidence

5 No economic studies were identified which were applicable to this review question.

6 Economic model

7 No economic modelling was undertaken for this review because the committee agreed that
8 other topics were higher priorities for economic evaluation.

9 Evidence statements

10 Economic

11 No economic studies were identified which were applicable to this review question.

12 The committee's discussion and interpretation of the evidence

13 The outcomes that matter most

14 Extent to which needs are met and quality of life were selected as critical outcomes by the
15 committee. Extent to which health, social care and educational needs are met was prioritised
16 as a critical outcome as the committee agreed that joined-up support should better enable
17 services to meet the needs of children and young people. Quality of life was chosen as a
18 critical outcome to capture the impact of joined-up services on degenerative health compared
19 to function.

20 Social inclusion, parallel planning/preparation for adulthood, choice of place for end of life
21 care, satisfaction with palliative and/or advance care and families' stress and anxiety were
22 chosen as important outcomes by the committee. Social inclusion was selected as an
23 important outcome by the committee because maintaining social relationships and
24 community participation may be beneficial for quality of life, but can be neglected due to a
25 focus on health provision. Parallel planning/preparation for adulthood was considered an
26 important outcome as the committee agreed there should be continued planning for life
27 alongside the end of life and that whether or not this occurs may be affected by different
28 service models. Choice of place for end of life care was chosen as an important outcome as
29 this may impact a number of other outcomes, such as quality of life and satisfaction, and is
30 not always offered to children and young people with severe complex needs and their
31 families or carers. Satisfaction was selected as an important outcome due to the importance
32 of providing person- and/or family-centred services. Finally, families' stress and anxiety was
33 chosen as an important outcome due to the propensity of these occurring when planning for,
34 or approaching, end of life and they may be impacted by different practice, service delivery or
35 commissioning models.

36 No evidence was found that reported social inclusion, parallel planning/preparation for
37 adulthood, choice of place for end of life care or families' stress and anxiety.

38 The quality of the evidence

39 The quality of the evidence was assessed with GRADE and was rated as very low. Concerns
40 about risk of bias were "very serious" for all outcomes. The most serious concerns were
41 biases arising from random sequence generation, allocation concealment, lack of a separate
42 control group, knowledge of the allocated interventions and incomplete outcome data. There

1 was “no serious inconsistency” for all outcomes due to only one study reporting each
2 outcome of interest. Indirectness ranged from “serious” to “no serious indirectness”.
3 Indirectness was due to a proportion of the population not having severe, complex needs in
4 all three areas (education, health and social care). Concerns about imprecision ranged from
5 “very serious” to “serious”. Imprecision was due to 95% confidence intervals crossing
6 boundaries for minimally important differences.

7 **Benefits and harms**

8 There was some limited evidence available that practice and service delivery models
9 including elements of care coordination and management such as communication and
10 referral between providers, shared care and decision making and interagency teams
11 improved emotional quality of life and the extent to which needs were met. However, the
12 evidence was very low quality and it was not possible to determine which aspects of the
13 practice and service delivery models potentially improved outcomes. Therefore, the
14 committee made recommendations based on their knowledge and experience.

15 The committee acknowledged that health services will be the first service to know when
16 children and young people with severe complex needs are progressing to end of life and
17 palliative care plans. They also agreed that sometimes other services are not notified when
18 this occurs and may not become aware until there are interruptions to services. Therefore,
19 the committee recommended that healthcare practitioners share this information with
20 education and social care practitioners to allow for more stable provision and improved
21 planning which should better meet the needs of children and young people. They also
22 recommended requesting a review of the EHC plan as the needs of the child or young
23 person may change as they progress to end of life and provision should reflect this [1.9.1].
24 Although the SEND Code of Practice (2015) specifies that EHC plans are reviewed when
25 there are significant changes in needs, the committee agreed that there is a widespread
26 belief that when children enter an end of life pathway, they don’t need much provision
27 beyond that offered by health services, specifically palliative care. This was supported by
28 moderate quality qualitative evidence that EHC plans are not always viewed as a live
29 document that requires review and updating (see evidence report K, sub-theme 12.4). In the
30 committee’s experience, community participation and maintaining social relationships may
31 still be very important to the child or young person but practitioners may overlook these and
32 prioritise technical aspects of care instead, so the committee agreed it was important to
33 promote the continued involvement of education and social care services and to focus on
34 maintaining the things that child or young person views as important. They felt an EHC plan
35 review was one method of ensuring this [1.9.4; 1.9.6]. Further, they felt strongly that children
36 and young people should be able to choose what support and activities they wish to continue
37 with and not have to continue with provision that does not meet their revised goals, such as
38 engaging with national curriculums, and that this may improve their quality of life [1.9.3]. The
39 committee also agreed it was important to train education and social care practitioners to
40 increase their knowledge and understanding of end of life and palliative care and parallel
41 planning work in order to best meet the changing needs of children and young people [1.9.8].
42 Finally, the committee agreed it was import to implement any new support as soon as
43 possible, rather than waiting until the EHC plan re-assessment is complete and the plan is
44 re-issued, due to the time pressures associated with end of life care [1.9.5]. This is consistent
45 with the SEND Code of Practice (2015) which states social care provision should be
46 delivered in line with statutory guidance and not be delayed until the EHC plan is complete.
47 Similarly, the committee agreed that regular joint reviews of palliative or end of life care plans
48 are needed as the child or young person’s needs can change frequently [1.9.7]. They were
49 not able to be more specific about the frequency of reviews because this would depend on
50 individual circumstances.

51 The committee agreed that whilst care and support of the child or young person is
52 paramount, it is important to consider the child in the context of their family. The family may
53 also need support during this time and this may be overlooked or families may not feel able

1 to seek support if it is not offered. Therefore, the committee agreed that finding out what
2 support family and carers need may help alleviate their stress and anxiety [1.9.2].

3 The committee acknowledged that there are a small number of children and young people
4 with severe complex needs who are, or would be, eligible for EHC plans but do not have a
5 plan due to young age or declining these services. Some recommendations would not apply
6 to this population due to a lack of engagement with specific services but the committee
7 agreed that other recommendations would still apply [1.9.2, 1.9.4; 1.9.8, 1.9.9].

8 **Cost effectiveness and resource use**

9 There was no published economic evidence for this review and no economic analysis was
10 undertaken.

11 The committee explained that when the palliative or end of life care plan is prepared there is
12 a need to think about whether the provision might need to change for a child or young person
13 and request a review of the EHC plan. Whilst the SEND Code of Practice (2015) specifies
14 EHC plans are reviewed when there are significant changes in needs, the committee
15 explained that this is not implemented consistently by services. There is a widespread
16 mistaken belief that children or young people entering the end of life pathway don't need
17 social care or education provision anymore.

18 The committee noted that the continuation of social care and education provision at end of
19 life may represent a change in practice. The committee explained that the capacity to
20 implement this is not held back by economic considerations but by organisational inefficiency
21 i.e. incoherence in organisational response and the lack of clarity about roles and
22 responsibilities. There is a lot of duplication across services e.g. various professionals having
23 more or less the same conversations with a child or young person and their families / carers.
24 If this process was done in a more coordinated way, the committee would expect to see
25 greater efficiency and reduction in the costs. The committee explained that it is also
26 important to consider the impacts beyond financial resources i.e. a child or a young person
27 has limited time left, so it's critical that what is left is not wasted with interagency
28 inefficiencies.

29 The committee explained that palliative care is changing all the time and even for health
30 professionals it is hard to keep up with what the changes are. The committee was of a view
31 that joint training would be useful to ensure that health, social care and education
32 practitioners have a good understanding of how palliative and end of life care and parallel
33 planning work. Such training would ensure that practitioners are able to provide better
34 support to those children and young people with severe complex needs who progress to end
35 of life, and their families. The committee explained that such training could be set up in an
36 interagency way and would not have significant cost implications. It was noted that anyone
37 who is experienced in providing palliative and end of life care could deliver such training. The
38 committee discussed the use of technology in delivering such training, for example videoing
39 consultants and experienced healthcare practitioners, and then making that video part of
40 annual training for larger groups of staff. The committee also discussed possibly including
41 such training as part of routine induction. This would minimise any cost implications while
42 maximising the impact.

43 The committee explained that an interagency team should find out what support the family
44 need at each stage of the palliative and end of life care pathway. All practitioners are trying to
45 be child-centred and meet their needs. However, the child or young person should be
46 considered in the context of their family, as whatever process the child is going through the
47 family will be going through the same. The committee also explained that families/carers can
48 feel a sense of guilt that their attention should be on the child and their needs are of
49 secondary importance. It was agreed that professionals should think how families can be
50 supported. This would usually involve signposting to other support services and would not
51 have resource implications. The committee explained that this will lead to improvements in

1 families', including siblings' or carers' quality of life at a minimal cost and would represent a
2 cost effective use of resources.

3 All other recommendations either represent current practice or relate to information provision
4 about matters relating to special educational needs and disability, which the SEND Code of
5 Practice (2015) requires local authorities to make arrangements for providing. Therefore,
6 they are not expected to result in additional resource use.

7 **Other factors the committee took into account**

8 The committee were aware of the NICE guideline on end of life care for infants, children and
9 young people with life-limiting conditions so included a cross-reference to recommendations
10 about general principles and decision making, care of the child or young person who is
11 approaching the end of life, and preferred place of death [1.9.9].

12 **Recommendations supported by this evidence review**

13 This evidence review supports recommendations 1.9.1 – 1.9.9.

14

15

1 References – included studies

2 Effectiveness

3 Hays 2006

4 Hays, R. M., Valentine, J., Haynes, G., Geyer, J. R., Villareale, N., McKinstry, B., Varni, J.
5 W., Churchill, S. S., The Seattle Pediatric Palliative Care Project: effects on family
6 satisfaction and health-related quality of life. *Journal of Palliative Medicine*, 9, 716-28, 2006

7 Horrocks 2002

8 Horrocks, S., Somerset, M., Salisbury, C., Do children with non-malignant life-threatening
9 conditions receive effective palliative care? A pragmatic evaluation of a local service.
10 *Palliative Medicine*, 16, 410-416, 2002

11 Other

12 Department for Education and Department for Health 2015

13 Department for Education and Department for Health, Special educational needs and
14 disability code of practice: 0 to 25 years. Statutory guidance for organisations which work
15 with and support children and young people who have special educational needs or
16 disabilities. Available at:
17 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND Code of Practice January 2015.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf) [Accessed 05/11/2020]
18

19 NICE 2016

20 National Institute for Health and Care Excellence, End of life care for infants, children and
21 young people with life-limiting conditions: planning and management, NG61, 2016

1 Appendices

2 Appendix A – Review protocol

3 **Review protocol for review question: What combined health, social care and education service delivery arrangements can**
 4 **best provide for the needs of disabled children and young people with severe complex needs on a palliative or advance**
 5 **care plan, and for the needs of their families and carers?**

6 **Table 3: Review protocol**

ID	Field	Content
0.	PROSPERO registration number	CRD42020186445
1.	Review title	What combined health, social care and education service delivery arrangements can best provide for the needs of disabled children and young people with severe complex needs on a palliative or advance care plan, and for the needs of their families and carers?
2.	Review question	What combined health, social care and education service delivery arrangements can best provide for the needs of disabled children and young people with severe complex needs on a palliative or advance care plan, and for the needs of their families and carers?
3.	Objective	To identify the most effective combined health, social care and education service delivery arrangements to meet the needs of disabled children and young people with severe complex needs on a palliative or advance care plan and their families and carers.
4.	Searches	The following databases will be searched: <ul style="list-style-type: none"> • Cochrane Central Register of Controlled Trials (CENTRAL) • Cochrane Database of Systematic Reviews (CDSR) • Embase • MEDLINE • Health Technology Assessment (HTA) • Database of Abstracts of Reviews of Effects (DARE) • British Education Index (BEI) • Educational Information Resources Center (ERIC) • Health Management Information Consortium (HMIC) • Applied Social Science Index and Abstracts (ASSIA) • Social Care Online • Social Policy and Practice

ID	Field	Content
		<ul style="list-style-type: none"> • Social Science Citation Index • Social Services Abstracts • Sociological Abstracts • PsycINFO • CINAHL • Emcare <p>Searches will be restricted by:</p> <ul style="list-style-type: none"> • Date: 2000 onwards • Language: English <p>Other searches:</p> <ul style="list-style-type: none"> • Inclusion lists of systematic reviews • Kings Fund Reports (https://www.kingsfund.org.uk/publications) • National Audit Office • Audit Commission • Open Grey (if insufficient studies are found from other sources) <p>The full search strategies for all databases will be published in the final review.</p>
5.	Condition or domain being studied	Disabled children and young people from birth to 25 years with severe complex needs on a palliative or advance care plan requiring health, social care and education support.
6.	Population	<p>Inclusion:</p> <p>Disabled children and young people from birth to 25 years with severe complex needs requiring health, social care and education support on a palliative or advance care plan</p> <p>Families and carers of disabled children and young people from birth to 25 years with severe complex needs requiring health, social care and education support on a palliative or advance care plan</p> <p>Exclusion: Disabled children and young people who are not on a palliative or advance care plan and/or do not have needs in all three areas of health, social care and education and their families and carers.</p>
7.	Intervention/Exposure/Test	<p>Any commissioning, practice and service delivery models (approaches, configurations of resources and services) delivering 2 or more of health, social care and education services.</p> <p>For example:</p>

ID	Field	Content
		<p>Practice and service delivery models</p> <ul style="list-style-type: none"> • Delivery arrangements: <ul style="list-style-type: none"> ○ Who provides care and how the healthcare workforce is managed: <ul style="list-style-type: none"> - Role-expansion/ task shifting ○ Coordination of care and management of care processes: <ul style="list-style-type: none"> - Individual case (service user) management (models responsive to individual needs) - Communication / referral between providers - Shared care - Shared decision making - Multidisciplinary teams - Multiagency assessment tool for service requirements (e.g. West Sussex tool) <p>Commissioning models:</p> <ul style="list-style-type: none"> • Delivery arrangements: <ul style="list-style-type: none"> ○ Coordination of care and management of care processes: <ul style="list-style-type: none"> - Integration (consolidation) of services • Financial arrangements: <ul style="list-style-type: none"> ○ Mechanisms for the payment of health services: <ul style="list-style-type: none"> - Joint/pooled budgets • Governance arrangements: <ul style="list-style-type: none"> ○ Authority and accountability for organisations: <ul style="list-style-type: none"> - Joint commissioning teams - Strategic oversight of commissioning
8.	Comparator/Reference standard/Confounding factors	<ul style="list-style-type: none"> • Any other joined-up commissioning, practice or service delivery models • Separate health, social and education services (without joined- up working or with some services not involved at all)
9.	Types of study to be included	<p>Systematic reviews of RCTs or non-randomised comparative studies (including cohort studies, before and after studies and interrupted time series), and RCTS will be included. Non-randomised studies will be included in the absence of RCTs for a given class of interventions. Service evaluations, process evaluations and audits will be included in the absence of comparative non-randomised studies.</p> <p>Conference abstracts will not be included.</p> <p>Non-randomised studies should adjust for confounders in their analysis such as: dominant provision (e.g.</p>

ID	Field	Content
		primarily autism, primarily physical disability), definitions of eligibility for service (e.g. for primary SEN), socioeconomic status. Studies will be downgraded for risk of bias if important confounding factors are not adequately adjusted for but will not be excluded for this reason.
10.	Other exclusion criteria	<p>Studies will not be included for the following reasons:</p> <ul style="list-style-type: none"> • Published prior to 2000 • Not published in the English language • Non Organisation for Economic Co-operation and Development (OCED) country (https://www.oecd.org/about/members-and-partners/) <p>Studies published prior to 2000 will not be considered due to legislative changes, specifically the Children and Families Care Act 2014, and the Aiming High for Disabled Children (AHDC) programme 2007. Studies published in languages other than English will not be considered due to time and resource constraints with translation.</p> <p>Studies published by non OCED countries will not be considered due to differences in health, social care and education services to those implemented in the UK.</p>
11.	Context	All settings will be considered where health, social care and education is provided for disabled children and young people from birth to 25 years with severe complex needs.
12.	Primary outcomes (critical outcomes)	<p>Critical Outcomes:</p> <ul style="list-style-type: none"> • Extent to which needs are met (including changing and evolving needs) (e.g., as measured by validated scales or whether EHC plans are met) • Health needs (e.g., mobility, pain, symptom management, temperament, emotional wellbeing, sleep) • Social care needs (e.g., self-care, safety, toileting) • Educational needs (e.g., communication aids) • Quality of life (both health- and social-related quality, and degenerative health versus function) (e.g., as measured by validated scales or assisted communication aids such as talking mats or 'it's all about me'; SDQ)
13.	Secondary outcomes (important outcomes)	<p>Important Outcomes:</p> <ul style="list-style-type: none"> • Social inclusion • Parallel planning/preparation for adulthood • Choice of place for end of life care • Satisfaction (child or young person and parent or carer) with palliative and/or advance care (e.g., as measured by validated scales) • Families stress and anxiety (e.g., as measured by validated scales)
14.	Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated.

ID	Field	Content
		<p>Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol.</p> <p>Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion.</p> <p>A standardised form will be used to extract data from studies. The following data will be extracted: study details (reference, country where study was carried out, type and dates), participant characteristics, inclusion and exclusion criteria, details of the interventions, setting and follow-up, relevant outcome data and source of funding. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.</p>
15.	Risk of bias (quality) assessment	<p>Quality assessment of individual studies will be performed using the following checklists:</p> <ul style="list-style-type: none"> • ROBIS tool for systematic reviews • Cochrane RoB tool v.2 for RCTs and quasi-RCTs • Cochrane ROBINS-I tool for non-randomised (clinical) controlled trials and cohort studies • Effective Practice and Organisation of Care (EPOC) RoB Tool for before and after studies • Effective Practice and Organisation of Care (EPOC) RoB Tool for interrupted time series <p>The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.</p>
16.	Strategy for data synthesis	<p>Intervention review:</p> <p>Quantitative findings will be formally summarised in the review. Where multiple studies report on the same outcome for the same comparison, meta-analyses will be conducted using Cochrane Review Manager software. A fixed effect meta-analysis will be conducted and data will be presented as risk ratios if possible or odds ratios when required (for example if only available in this form in included studies) for dichotomous outcomes, and mean differences or standardised mean differences for continuous outcomes. Heterogeneity in the effect estimates of the individual studies will be assessed using the I² statistic. I² values of greater than 50% and 80% will be considered as significant and very significant heterogeneity, respectively. Heterogeneity will be explored as appropriate using sensitivity analyses. If heterogeneity cannot be explained through sensitivity analysis then a random effects model will be used for meta-analysis, or the data will not be pooled if the I² statistic is greater than 80%.</p> <p>The confidence in the findings across all available evidence will be evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group: http://www.gradeworkinggroup.org/</p> <p>Minimally important differences:</p> <p>We will check the rehabilitation measures database (www.sralab.org) for published MIDs for scales reported by included studies and use these if available. If not, we will use GRADE default MIDs.</p> <p>For all remaining continuous outcomes, we will use GRADE default MID of 0.5 times SD of the control groups at baseline (or at follow-up if the SD is not available a baseline). For all remaining dichotomous</p>

ID	Field	Content		
		outcomes (RRs, ORs and HRs), we will use the GRADE default for RRs of 0.8 and 1.25 for consistency.		
17.	Analysis of sub-groups	N/A		
18.	Type and method of review	<input checked="" type="checkbox"/>	Intervention	
		<input type="checkbox"/>	Diagnostic	
		<input type="checkbox"/>	Prognostic	
		<input type="checkbox"/>	Qualitative	
		<input type="checkbox"/>	Epidemiologic	
		<input checked="" type="checkbox"/>	Service Delivery	
		<input type="checkbox"/>	Other (please specify)	
19.	Language	English		
20.	Country	England		
21.	Anticipated or actual start date	12/05/20		
22.	Anticipated completion date	May 2021		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	<input type="checkbox"/>	<input type="checkbox"/>
		Piloting of the study selection process	<input type="checkbox"/>	<input type="checkbox"/>
		Formal screening of search results against eligibility criteria	<input type="checkbox"/>	<input type="checkbox"/>
		Data extraction	<input type="checkbox"/>	<input type="checkbox"/>
		Risk of bias (quality) assessment	<input type="checkbox"/>	<input type="checkbox"/>
		Data analysis	<input type="checkbox"/>	<input type="checkbox"/>
24.	Named contact	5a. Named contact National Guideline Alliance		
		5b Named contact e-mail CYPseverecomplexneeds@nice.org.uk		
		5e Organisational affiliation of the review		

ID	Field	Content
		National Institute for Health and Care Excellence (NICE) and National Guideline Alliance
25.	Review team members	National Guideline Alliance
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance which receives funding from NICE.
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual . Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10113
29.	Other registration details	None
30.	Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020186445
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: notifying registered stakeholders of publication publicising the guideline through NICE's newsletter and alerts issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.
32.	Keywords	Child, infant, young person, disability, health care, education, social care, service delivery, service organisation
33.	Details of existing review of same topic by same authors	None
34.	Current review status	<input checked="" type="checkbox"/> Ongoing
		<input type="checkbox"/> Completed but not published
		<input type="checkbox"/> Completed and published

ID	Field	Content
		<input type="checkbox"/> Completed, published and being updated
		<input type="checkbox"/> Discontinued
35..	Additional information	None
36.	Details of final publication	www.nice.org.uk

1 AHDC: Aiming High for Disabled Children; ASSIA: Applied Social Science Index and Abstracts; BEI: British Education Index; CDSR: Cochrane Database of Systematic
2 Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; CINAHL: Cumulative Index to Nursing & Allied Health; DARE: Database of Abstracts of Reviews of
3 Effects; EHC: education, health and care; EPOC: Effective Practice and Organisation of Care; ERIC: Educational Information Resources Center; ERIC: Educational Information
4 Resources Center; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HMIC: Health Management Information Consortium; HR: hazard ratio;
5 HTA: Health Technology Assessment; MID: minimally important difference; NICE: National Institute for Health and Care Excellence; OECD: Organisation for Economic Co-
6 operation and Development; OR: odds ratio; RCT: randomised controlled trial; RoB: risk of bias; ROBINS-I: risk of bias in non-randomised studies – of interventions; ROBIS:
7 Risk of Bias in Systematic Reviews; RR: risk ratio; SD: standard deviation; SDQ: Strengths and Difficulties Questionnaire; SEN: special educational needs

1 Appendix B – Literature search strategies

2 Literature search strategies for review question: What combined health, social
3 care and education service delivery arrangements can best provide for the
4 needs of disabled children and young people with severe complex needs on a
5 palliative or advance care plan, and for the needs of their families and carers?

6 Databases: Medline; Medline Epub Ahead of Print; and Medline In-Process &
7 Other Non-Indexed Citations

8 Date of last search: 19/06/2020

#	Searches
1	ADOLESCENT/ or MINORS/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$.ti,ab.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
7	exp PEDIATRICS/
8	p?ediatric\$.ti,ab.
9	YOUNG ADULT/
10	young\$ adult?.ti,ab.
11	or/1-10
12	exp DISABLED PERSONS/
13	exp MENTAL DISORDERS/
14	exp COMMUNICATION DISORDERS/
15	exp INTELLECTUAL DISABILITY/
16	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$.ti.
17	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
18	SHCN.ti,ab.
19	or/12-18
20	11 and 19
21	DISABLED CHILDREN/
22	CSHCN.ti,ab.
23	"Education Health and Care plan?".ti,ab.
24	EHC plan?.ti,ab.
25	EHCP?.ti,ab.
26	or/20-25
27	INTERINSTITUTIONAL RELATIONS/
28	INTERSECTORAL COLLABORATION/
29	"DELIVERY OF HEALTH CARE, INTEGRATED"/
30	(interinstitution\$ or multiinstitution\$ or jointinstitution\$.ti,ab.
31	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$.ti,ab.
32	(intersector\$ or multisector\$ or jointsector\$.ti,ab.
33	(interagenc\$ or multiagenc\$ or jointagenc\$.ti,ab.
34	(interprovider? or multiprovider? or jointprovider?).ti,ab.
35	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
36	(interprofession\$ or multiprofession\$ or jointprofession\$.ti,ab.
37	((inter or multi\$ or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$)).ti,ab.
38	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti,ab.
39	or/27-38
40	(HEALTH SERVICES/ or CHILD HEALTH SERVICES/ or ADOLESCENT HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or HOME CARE SERVICES/ or HEALTH SERVICES FOR PEOPLE WITH DISABILITIES/ or MENTAL HEALTH SERVICES/ or NURSING SERVICES/ or exp HEALTH PERSONNEL/) and (exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/)
41	(HEALTH SERVICES/ or CHILD HEALTH SERVICES/ or ADOLESCENT HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or HOME CARE SERVICES/ or HEALTH SERVICES FOR PEOPLE WITH DISABILITIES/ or MENTAL HEALTH SERVICES/ or NURSING SERVICES/ or exp HEALTH PERSONNEL/) and (EDUCATION/ or exp EDUCATION, SPECIAL/ or SCHOOLS/ or SCHOOL HEALTH SERVICES/ or SCHOOLS, NURSERY/ or exp NURSERY/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
42	(exp SOCIAL WORK/ or SOCIAL WORK, PSYCHIATRIC/ or SOCIAL WORKERS/) and (EDUCATION/ or exp EDUCATION, SPECIAL/ or SCHOOLS/ or SCHOOL HEALTH SERVICES/ or SCHOOLS, NURSERY/ or exp

#	Searches
	NURSERIES/ or CHILD DAY CARE CENTERS/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or SCHOOL TEACHERS/)
43	or/40-42
44	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj10 social\$ adj10 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
45	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj10 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj10 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
46	(social\$ adj10 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj10 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
47	or/44-46
48	STATE MEDICINE/og [Organization & Administration]
49	CHILD HEALTH SERVICES/og [Organization & Administration]
50	ADOLESCENT HEALTH SERVICES/og [Organization & Administration]
51	EDUCATION/og [Organization & Administration]
52	exp EDUCATION, SPECIAL/og [Organization & Administration]
53	exp SOCIAL WORK/og [Organization & Administration]
54	or/48-53
55	TERMINALLY ILL/
56	ADVANCE CARE PLANNING/
57	ADVANCE DIRECTIVES/
58	LIVING WILLS/
59	RESUSCITATION ORDERS/
60	TERMINAL CARE/
61	PALLIATIVE CARE/
62	HOSPICE CARE/
63	((terminal\$ or advance\$ or incurable or life limit\$ or life threaten\$ or life shorten\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
64	(end adj3 life).ti,ab.
65	dying.ti,ab.
66	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
67	(last year of life or LYOL or life\$ end).ti,ab.
68	((advanced or late or last or end or final or terminal) adj (phase\$ or stage?)).ti,ab.
69	advance? care plan\$.ti,ab.
70	advance? directive?.ti,ab.
71	living will?.ti,ab.
72	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab.
73	(terminal\$ adj3 (care\$ or caring)).ti,ab.
74	palliat\$.ti,ab.
75	hospice?.ti,ab.
76	or/55-75
77	ADVANCE CARE PLANNING/og [Organization & Administration]
78	TERMINAL CARE/og [Organization & Administration]
79	PALLIATIVE CARE/og [Organization & Administration]
80	HOSPICE CARE/og [Organization & Administration]
81	or/77-80
82	(palliat\$ adj3 service? adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
83	((charit\$ or third sector or non-government\$ organi\$ or NGO? or non-profit\$ organi\$ or not-for-profit organi\$ or volunt\$ or communit\$ or social enterprise or VCSE) adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
84	26 and (39 or 43 or 47 or 54) and 76
85	26 and 81
86	11 and 82
87	26 and 76 and 83
88	or/84-87
89	limit 88 to english language
90	limit 89 to yr="2000 -Current"
91	LETTER/

#	Searches
92	EDITORIAL/
93	NEWS/
94	exp HISTORICAL ARTICLE/
95	ANECDOTES AS TOPIC/
96	COMMENT/
97	CASE REPORT/
98	(letter or comment*).ti.
99	or/91-98
100	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
101	99 not 100
102	ANIMALS/ not HUMANS/
103	exp ANIMALS, LABORATORY/
104	exp ANIMAL EXPERIMENTATION/
105	exp MODELS, ANIMAL/
106	exp RODENTIA/
107	(rat or rats or mouse or mice).ti.
108	or/101-107
109	90 not 108

1

2 Databases: Embase; and Embase Classic

3 Date of last search: 19/06/2020

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
7	exp PEDIATRICS/
8	p?ediatric\$.ti,ab.
9	YOUNG ADULT/
10	young\$ adult?.ti,ab.
11	or/1-10
12	exp DISABLED PERSON/
13	exp MENTAL DISEASE/
14	INTELLECTUAL IMPAIRMENT/
15	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$.ti.
16	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
17	SHCN.ti,ab.
18	or/12-17
19	11 and 18
20	HANDICAPPED CHILD/
21	CSHCN.ti,ab.
22	"Education Health and Care plan?".ti,ab.
23	EHC plan?.ti,ab.
24	EHCP?.ti,ab.
25	or/19-24
26	PUBLIC RELATIONS/
27	INTERSECTORAL COLLABORATION/
28	INTEGRATED HEALTH CARE SYSTEM/
29	(interinstitution\$ or multiinstitution\$ or jointinstitution\$).ti,ab.
30	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$).ti,ab.
31	(intersector\$ or multisector\$ or jointsector\$).ti,ab.
32	(interagenc\$ or multiagenc\$ or jointagenc\$).ti,ab.
33	(interprovider? or multiprovider? or jointprovider?).ti,ab.
34	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
35	(interprofession\$ or multiprofession\$ or jointprofession\$).ti,ab.
36	((inter or multi\$ or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$)).ti,ab.
37	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
38	or/26-37
39	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL) and (SOCIAL CARE/ or SOCIAL WORK/ or

#	Searches
	SOCIAL WORKER/)
40	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
41	(SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
42	or/39-41
43	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
44	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
45	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
46	or/43-45
47	NATIONAL HEALTH SERVICE/ and ORGANIZATION/
48	CHILD HEALTH CARE/ and ORGANIZATION/
49	EDUCATION/ and ORGANIZATION/
50	exp SPECIAL EDUCATION/ and ORGANIZATION/
51	SOCIAL WORK/ and ORGANIZATION/
52	or/47-51
53	TERMINALLY ILL PATIENT/
54	HOSPICE PATIENT/
55	ADVANCE CARE PLANNING/
56	LIVING WILL/
57	TERMINAL CARE/
58	*PALLIATIVE THERAPY/
59	HOSPICE CARE/
60	((terminal\$ or advance\$ or incurable or life limit\$ or life threaten\$ or life shorten\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
61	(end adj3 life).ti,ab.
62	dying.ti,ab.
63	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
64	(last year of life or LYOL or life\$ end).ti,ab.
65	((advanced or late or last or end or final or terminal) adj (phase\$ or stage?)).ti,ab.
66	advance? care plan\$.ti,ab.
67	advance? directive?.ti,ab.
68	living will?.ti,ab.
69	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab.
70	(terminal\$ adj3 (care\$ or caring)).ti,ab.
71	palliat\$.ti,ab.
72	hospice?.ti,ab.
73	or/53-72
74	ADVANCE CARE PLANNING/ and ORGANIZATION/
75	TERMINAL CARE/ and ORGANIZATION/
76	*PALLIATIVE THERAPY/ and ORGANIZATION/
77	HOSPICE CARE/ and ORGANIZATION/
78	or/74-77
79	(palliat\$ adj3 service? adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
80	((charit\$ or third sector or non-government\$ organi\$ or NGO? or non-profit\$ organi\$ or not-for-profit organi\$ or volunt\$ or communit\$ or social enterprise or VCSE) adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
81	25 and (38 or 42 or 46 or 52) and 73
82	25 and 78

#	Searches
83	11 and 79
84	25 and 73 and 80
85	or/81-84
86	limit 85 to english language
87	limit 86 to yr="2000 -Current"
88	letter.pt. or LETTER/
89	note.pt.
90	editorial.pt.
91	CASE REPORT/ or CASE STUDY/
92	(letter or comment*).ti.
93	or/88-92
94	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
95	93 not 94
96	ANIMAL/ not HUMAN/
97	NONHUMAN/
98	exp ANIMAL EXPERIMENT/
99	exp EXPERIMENTAL ANIMAL/
100	ANIMAL MODEL/
101	exp RODENT/
102	(rat or rats or mouse or mice).ti.
103	or/95-102
104	87 not 103

1

2 Database: Health Management Information Consortium (HMIC)

3 Date of last search: 19/06/2020

#	Searches
1	exp YOUNG PEOPLE/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$.ti,ab.
3	exp CHILDREN/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
5	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
6	exp PAEDIATRICS/
7	p?ediatric\$.ti,ab.
8	YOUNG ADULTS/
9	young\$ adult?.ti,ab.
10	or/1-9
11	DISABLED PEOPLE/
12	exp DISABILITIES/
13	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$.ti.
14	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
15	SHCN.ti,ab.
16	or/11-15
17	10 and 16
18	CSHCN.ti,ab.
19	"Education Health and Care plan?".ti,ab.
20	EHC plan?.ti,ab.
21	EHCP?.ti,ab.
22	or/17-21
23	COLLABORATION/
24	exp INTERAGENCY COLLABORATION/
25	INTERPROFESSIONAL COLLABORATION/
26	COLLABORATIVE CARE/
27	INTEGRATED PROVIDERS/
28	INTEGRATED CARE/
29	INTERDISCIPLINARY SERVICES/
30	JOINT WORKING/
31	HEALTH & SOCIAL SERVICES INTERACTION/
32	COMMUNICATION/
33	HEALTH SERVICE PROVISION/
34	(interinstitution\$ or multiinstitution\$ or jointinstitution\$.ti,ab.
35	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$.ti,ab.
36	(intersector\$ or multisector\$ or jointsector\$.ti,ab.
37	(interagenc\$ or multiagenc\$ or jointagenc\$.ti,ab.
38	(interprovider? or multiprovider? or jointprovider?).ti,ab.

#	Searches
39	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
40	(interprofession\$ or multiprofession\$ or jointprofession\$).ti,ab.
41	((inter or multi\$ or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$)).ti,ab.
42	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
43	or/23-42
44	(HEALTH SERVICES/ or exp CHILD HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or exp MENTAL HEALTH SERVICES/ or NURSING CARE/ or exp HEALTH SERVICE STAFF/) and (exp SOCIAL WORK/ or SOCIAL WORK SERVICE/ or SOCIAL WORK PROFESSION/ or SOCIAL WORKERS/ or exp SOCIAL WORKER TEAMS/ or SOCIAL CARE/ or exp SOCIAL CARE SERVICES/ or SOCIAL SERVICES/ or SOCIAL SERVICES DEPARTMENTS/ or SUPPORTIVE SOCIAL WORK/)
45	(HEALTH SERVICES/ or exp CHILD HEALTH SERVICES/ or COMMUNITY HEALTH SERVICES/ or exp MENTAL HEALTH SERVICES/ or NURSING CARE/ or exp HEALTH SERVICE STAFF/) and (EDUCATION/ or PRIMARY EDUCATION/ or SECONDARY EDUCATION/ or exp SPECIAL EDUCATION/ or exp SCHOOLS/ or exp SCHOOL HEALTH SERVICES/ or exp NURSERIES/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or TEACHERS/)
46	(exp SOCIAL WORK/ or SOCIAL WORK SERVICE/ or SOCIAL WORK PROFESSION/ or SOCIAL WORKERS/ or exp SOCIAL WORKER TEAMS/ or SOCIAL CARE/ or exp SOCIAL CARE SERVICES/ or SOCIAL SERVICES/ or SOCIAL SERVICES DEPARTMENTS/ or SUPPORTIVE SOCIAL WORK/) and (EDUCATION/ or PRIMARY EDUCATION/ or SECONDARY EDUCATION/ or exp SPECIAL EDUCATION/ or exp SCHOOLS/ or exp SCHOOL HEALTH SERVICES/ or exp NURSERIES/ or UNIVERSITIES/ or TEACHING/ or REMEDIAL TEACHING/ or TEACHERS/)
47	or/44-46
48	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
49	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
50	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
51	or/48-50
52	TERMINAL ILLNESS/
53	ADVANCE CARE PLANNING/
54	ADVANCE DIRECTIVES/
55	LIVING WILLS/
56	TERMINAL CARE/
57	PALLIATIVE CARE/
58	END OF LIFE CARE/
59	HOSPICE CARE/
60	TERMINAL CARE HOSPITALS/
61	((terminal\$ or advance\$ or incurable or life limit\$ or life threaten\$ or life shorten\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
62	(end adj3 life).ti,ab.
63	dying.ti,ab.
64	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
65	(last year of life or LYOL or life\$ end).ti,ab.
66	((advanced or late or last or end or final or terminal) adj (phase\$ or stage?)).ti,ab.
67	advance? care plan\$.ti,ab.
68	advance? directive?.ti,ab.
69	living will?.ti,ab.
70	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab.
71	(terminal\$ adj3 (care\$ or caring)).ti,ab.
72	palliat\$.ti,ab.
73	hospice?.ti,ab.
74	or/52-73
75	(palliat\$ adj3 service? adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
76	((charit\$ or third sector or non-government\$ organi\$ or NGO? or non-profit\$ organi\$ or not-for-profit organi\$ or volunt\$ or communit\$ or social enterprise or VCSE) adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.

#	Searches
77	22 and (43 or 47 or 51) and 74
78	10 and 75
79	22 and 74 and 76
80	or/77-79
81	limit 80 to yr="2000 -Current"

1

2 Database: Social Policy and Practice

3 Date of last search: 19/06/2020

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$.ti,ab.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
4	p?ediatric\$.ti,ab.
5	young\$ adult?.ti,ab.
6	or/1-5
7	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$.ti.
8	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
9	SHCN.ti,ab.
10	or/7-9
11	6 and 10
12	CSHCN.ti,ab.
13	"Education Health and Care plan?".ti,ab.
14	EHC plan?.ti,ab.
15	EHCP?.ti,ab.
16	or/11-15
17	(interinstitution\$ or multiinstitution\$ or jointinstitution\$.ti,ab.
18	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$.ti,ab.
19	(intersector\$ or multisector\$ or jointsector\$.ti,ab.
20	(interagenc\$ or multiagenc\$ or jointagenc\$.ti,ab.
21	(interprovider? or multiprovider? or jointprovider?).ti,ab.
22	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
23	(interprofession\$ or multiprofession\$ or jointprofession\$.ti,ab.
24	((inter or multi\$ or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$)).ti,ab.
25	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
26	or/17-25
27	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
28	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
29	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
30	or/27-29
31	((terminal\$ or advance\$ or incurable or life limit\$ or life threaten\$ or life shorten\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
32	(end adj3 life).ti,ab.
33	dying.ti,ab.
34	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
35	(last year of life or LYOL or life\$ end).ti,ab.
36	((advanced or late or last or end or final or terminal) adj (phase\$ or stage?)).ti,ab.
37	advance? care plan\$.ti,ab.
38	advance? directive?.ti,ab.

#	Searches
39	living will?.ti,ab.
40	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab.
41	(terminal\$ adj3 (care\$ or caring)).ti,ab.
42	palliat\$.ti,ab.
43	hospice?.ti,ab.
44	or/31-43
45	(palliat\$ adj3 service? adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
46	((charit\$ or third sector or non-government\$ organi\$ or NGO? or non-profit\$ organi\$ or not-for-profit organi\$ or volunt\$ or communit\$ or social enterprise or VCSE) adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
47	16 and (26 or 30) and 44
48	6 and 45
49	16 and 44 and 46
50	or/47-49
51	limit 50 to yr="2000 -Current"

1

2 Database: PsycInfo

3 Date of last search: 19/06/2020

#	Searches
1	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab.
2	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
3	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
4	PEDIATRICS/
5	p?ediatric\$.ti,ab.
6	young\$ adult?.ti,ab.
7	or/1-6
8	DISORDERS/
9	exp DISABILITIES/
10	PHYSICAL DISORDERS/
11	exp SENSE ORGAN DISORDERS/
12	exp MENTAL DISORDERS/
13	exp COMMUNICATION DISORDERS/
14	SPECIAL NEEDS/
15	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunc\$).ti.
16	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
17	SHCN.ti,ab.
18	or/8-17
19	7 and 18
20	CSHCN.ti,ab.
21	"Education Health and Care plan?".ti,ab.
22	EHC plan?.ti,ab.
23	EHCP?.ti,ab.
24	or/19-23
25	INTEGRATED SERVICES/
26	INTERDISCIPLINARY TREATMENT APPROACH/
27	(interinstitution\$ or multiinstitution\$ or jointinstitution\$).ti,ab.
28	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$).ti,ab.
29	(intersector\$ or multisector\$ or jointsector\$).ti,ab.
30	(interagenc\$ or multiagenc\$ or jointagenc\$).ti,ab.
31	(interprovider? or multiprovider? or jointprovider?).ti,ab.
32	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
33	(interprofession\$ or multiprofession\$ or jointprofession\$).ti,ab.
34	((inter or multi\$ or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$)).ti,ab.
35	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
36	or/25-35
37	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/)
38	(HEALTH CARE SERVICES/ or COMMUNITY SERVICES/ or HOME CARE/ or MENTAL HEALTH SERVICES/ or COMMUNITY MENTAL HEALTH SERVICES/ or NURSING/ or exp HEALTH PERSONNEL/) and (EDUCATION/ or

#	Searches
	ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
39	(exp SOCIAL CASEWORK/ or exp SOCIAL WORKERS/) and (EDUCATION/ or ELEMENTARY EDUCATION/ or MIDDLE SCHOOL EDUCATION/ or HIGH SCHOOL EDUCATION/ or SECONDARY EDUCATION/ or HIGHER EDUCATION/ or SPECIAL EDUCATION/ or "MAINSTREAMING (EDUCATIONAL)"/ or REMEDIAL EDUCATION/ or exp SCHOOLS/ or TEACHING/ or TEACHERS/ or PRESCHOOL TEACHERS/ or ELEMENTARY SCHOOL TEACHERS/ or JUNIOR HIGH SCHOOL TEACHERS/ or MIDDLE SCHOOL TEACHERS/ or HIGH SCHOOL TEACHERS/ or COLLEGE TEACHERS/ or VOCATIONAL EDUCATION TEACHERS/ or SPECIAL EDUCATION TEACHERS/)
40	or/37-39
41	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
42	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
43	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
44	or/41-43
45	TERMINALLY ILL PATIENTS/
46	ADVANCE DIRECTIVES/
47	PALLIATIVE CARE/
48	((terminal\$ or advance\$ or incurable or life limit\$ or life threaten\$ or life shorten\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
49	(end adj3 life).ti,ab.
50	dying.ti,ab.
51	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
52	(last year of life or LYOL or life\$ end).ti,ab.
53	((advanced or late or last or end or final or terminal) adj (phase\$ or stage?)).ti,ab.
54	advance? care plan\$.ti,ab.
55	advance? directive?.ti,ab.
56	living will?.ti,ab.
57	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab.
58	(terminal\$ adj3 (care\$ or caring)).ti,ab.
59	palliat\$.ti,ab.
60	hospice?.ti,ab.
61	or/45-60
62	(palliat\$ adj3 service? adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
63	((charit\$ or third sector or non-government\$ organi\$ or NGO? or non-profit\$ organi\$ or not-for-profit organi\$ or volunt\$ or communit\$ or social enterprise or VCSE) adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
64	24 and (36 or 40 or 44) and 61
65	7 and 62
66	24 and 61 and 63
67	or/64-66
68	limit 67 to english language
69	limit 68 to yr="2000 -Current"
70	limit 69 to ("0100 journal" or "0110 peer-reviewed journal" or "0120 non-peer-reviewed journal")

1

2 Database: Emcare

3 Date of last search: 19/06/2020

#	Searches
1	exp ADOLESCENT/
2	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab.
3	exp CHILD/
4	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab.
5	exp INFANT/
6	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab.
7	exp PEDIATRICS/
8	p?ediatric\$.ti,ab.
9	YOUNG ADULT/
10	young\$ adult?.ti,ab.
11	or/1-10
12	exp DISABLED PERSON/
13	exp MENTAL DISEASE/
14	INTELLECTUAL IMPAIRMENT/
15	(disable? or disabilit\$ or handicap\$ or retard\$ or disorder? or impair\$ or condition? or difficulty or difficulties or deficit? or dysfunct\$).ti.
16	((sever\$ or complex\$ or special or high) adj3 need?).ti,ab.
17	SHCN.ti,ab.
18	or/12-17
19	11 and 18
20	HANDICAPPED CHILD/
21	CSHCN.ti,ab.
22	"Education Health and Care plan?".ti,ab.
23	EHC plan?.ti,ab.
24	EHCP?.ti,ab.
25	or/19-24
26	PUBLIC RELATIONS/
27	INTERSECTORAL COLLABORATION/
28	INTEGRATED HEALTH CARE SYSTEM/
29	(interinstitution\$ or multiinstitution\$ or jointinstitution\$).ti,ab.
30	(interorgani?ation\$ or multiorgani?ation\$ or jointorgani?ation\$).ti,ab.
31	(intersector\$ or multisector\$ or jointsector\$).ti,ab.
32	(interagenc\$ or multiagenc\$ or jointagenc\$).ti,ab.
33	(interprovider? or multiprovider? or jointprovider?).ti,ab.
34	(interstakeholder? or multistakeholder? or jointstakeholder?).ti,ab.
35	(interprofession\$ or multiprofession\$ or jointprofession\$).ti,ab.
36	((inter or multi\$ or joint) adj3 (institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$)).ti,ab.
37	((institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or stakeholder? or profession\$ or care or service? or department\$) adj5 (collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partner\$)).ti.
38	or/26-37
39	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL/) and (SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/)
40	(HEALTH SERVICE/ or CHILD HEALTH CARE/ or COMMUNITY CARE/ or HOME CARE/ or MENTAL HEALTH SERVICE/ or *NURSING/ or exp HEALTH CARE PERSONNEL/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
41	(SOCIAL CARE/ or SOCIAL WORK/ or SOCIAL WORKER/) and (EDUCATION/ or exp SPECIAL EDUCATION/ or SCHOOL/ or SCHOOL HEALTH SERVICE/ or NURSERY SCHOOL/ or NURSERY/ or KINDERGARTEN/ or PRIMARY SCHOOL/ or MIDDLE SCHOOL/ or HIGH SCHOOL/ or COLLEGE/ or COMMUNITY COLLEGE/ or UNIVERSITY/ or TEACHING/ or exp TEACHER/)
42	or/39-41
43	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 social\$ adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
44	((health\$ or NHS or clinical or clinician? or medical or medic? or physician? or consultant? or nurse? or general practitioner? or GP? or occupational therapist? or OT? or allied health professional? or AHP? or ((speech or language) adj3 therapist?) or SLT?) adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$ or deliver\$)).ti,ab.
45	(social\$ adj5 (educat\$ or school\$ or teach\$ or headmaster? or headmistress\$ or SENCO? or DfE?) adj5 (care or service? or department? or institution\$ or organi?ation\$ or sector\$ or agenc\$ or provider? or policy or policies or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter or multi or joint\$ or across or share? or sharing or together or communicat\$ or barrier? or facilitat\$

#	Searches
	or deliver\$)).ti,ab.
46	or/43-45
47	NATIONAL HEALTH SERVICE/ and ORGANIZATION/
48	CHILD HEALTH CARE/ and ORGANIZATION/
49	EDUCATION/ and ORGANIZATION/
50	exp SPECIAL EDUCATION/ and ORGANIZATION/
51	SOCIAL WORK/ and ORGANIZATION/
52	or/47-51
53	TERMINALLY ILL PATIENT/
54	HOSPICE PATIENT/
55	ADVANCE CARE PLANNING/
56	LIVING WILL/
57	TERMINAL CARE/
58	*PALLIATIVE THERAPY/
59	HOSPICE CARE/
60	((terminal\$ or advance\$ or incurable or life limit\$ or life threaten\$ or life shorten\$) adj3 (ill\$ or disease\$ or condition\$)).ti,ab.
61	(end adj3 life).ti,ab.
62	dying.ti,ab.
63	((approach\$ or close\$ or near\$ or imminent\$ or impending) adj3 death).ti,ab.
64	(last year of life or LYOL or life\$ end).ti,ab.
65	((advanced or late or last or end or final or terminal) adj (phase\$ or stage?)).ti,ab.
66	advance? care plan\$.ti,ab.
67	advance? directive?.ti,ab.
68	living will?.ti,ab.
69	(resuscitat\$ adj3 (policies or policy or order? or decision? or withhold\$)).ti,ab.
70	(terminal\$ adj3 (care\$ or caring)).ti,ab.
71	palliat\$.ti,ab.
72	hospice?.ti,ab.
73	or/53-72
74	ADVANCE CARE PLANNING/ and ORGANIZATION/
75	TERMINAL CARE/ and ORGANIZATION/
76	*PALLIATIVE THERAPY/ and ORGANIZATION/
77	HOSPICE CARE/ and ORGANIZATION/
78	or/74-77
79	(palliat\$ adj3 service? adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
80	((charit\$ or third sector or non-government\$ organi\$ or NGO? or non-profit\$ organi\$ or not-for-profit organi\$ or volunt\$ or communit\$ or social enterprise or VCSE) adj5 (involv\$ or collaborat\$ or coordinat\$ or co-ordinat\$ or cooperat\$ or co-operat\$ or integrat\$ or partnership? or partnering or network\$ or inter\$ or multi\$ or joint\$ or across or share? or sharing or together or communicat\$)).ti,ab.
81	25 and (38 or 42 or 46 or 52) and 73
82	25 and 78
83	11 and 79
84	25 and 73 and 80
85	or/81-84
86	limit 85 to english language
87	limit 86 to yr="2000 -Current"
88	letter.pt. or LETTER/
89	note.pt.
90	editorial.pt.
91	CASE REPORT/ or CASE STUDY/
92	(letter or comment*).ti.
93	or/88-92
94	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
95	93 not 94
96	ANIMAL/ not HUMAN/
97	NONHUMAN/
98	exp ANIMAL EXPERIMENT/
99	exp EXPERIMENTAL ANIMAL/
100	ANIMAL MODEL/
101	exp RODENT/
102	(rat or rats or mouse or mice).ti.
103	or/95-102
104	87 not 103

1 **Databases: Cochrane Central Register of Controlled Trials (CCTR); and Cochrane
2 Database of Systematic Reviews (CDSR)**

3 **Date of last search: 19/06/2020**

#	Searches
#1	[mh ^"ADOLESCENT"]
#2	[mh ^"MINORS"]
#3	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*):ti,ab
#4	[mh "CHILD"]
#5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*):ti,ab
#6	[mh "INFANT"]
#7	(infan* or neonat* or newborn* or baby or babies):ti,ab
#8	[mh "PEDIATRICS"]
#9	(pediatric* or paediatric*):ti,ab
#10	[mh ^"YOUNG ADULT"]
#11	"young\$ adult*":ti,ab
#12	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11
#13	[mh "DISABLED PERSONS"]
#14	[mh "MENTAL DISORDERS"]
#15	[mh "COMMUNICATION DISORDERS"]
#16	[mh "INTELLECTUAL DISABILITY"]
#17	(disable* or disabilit* or handicap* or retard* or disorder* or impair* or condition* or difficulty or difficulties or deficit* or dysfunct*):ti
#18	((sever* or complex* or special or high) near/3 (need or needs)):ti,ab
#19	SHCN:ti,ab
#20	#13 or #14 or #15 or #16 or #17 or #18 or #19
#21	#12 and #20
#22	[mh ^"DISABLED CHILDREN"]
#23	CSHCN:ti,ab
#24	"Education Health and Care plan*":ti,ab
#25	EHC plan*:ti,ab
#26	EHCP*:ti,ab
#27	#21 or #22 or #23 or #24 or #25 or #26
#28	[mh ^"INTERINSTITUTIONAL RELATIONS"]
#29	[mh ^"INTERSECTORAL COLLABORATION"]
#30	[mh ^"DELIVERY OF HEALTH CARE, INTEGRATED"]
#31	(interinstitution* or multiinstitution* or jointinstitution*):ti,ab
#32	(interorganisation* or interorganization* or multiorganisation* or multiorganization* or jointorganisation* or jointorganization*):ti,ab
#33	(intersector* or multisector* or jointsector*):ti,ab
#34	(interagenc* or multiagenc* or jointagenc*):ti,ab
#35	(interprovider* or multiprovider* or jointprovider*):ti,ab
#36	(interstakeholder* or multistakeholder* or jointstakeholder*):ti,ab
#37	(interprofession* or multiprofession* or jointprofession*):ti,ab
#38	((inter or multi or joint) near/3 (institution* or organisation* or organization* or sector* or agenc* or provider? or stakeholder? or profession*):ti,ab
#39	((institution* or organisation* or organization* or sector* or agenc* or provider? or stakeholder? or profession* or care or service* or department*) near/5 (collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partner*)):ti
#40	#28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39
#41	([mh ^"HEALTH SERVICES"] or [mh ^"CHILD HEALTH SERVICES"] or [mh ^"ADOLESCENT HEALTH SERVICES"] or [mh ^"COMMUNITY HEALTH SERVICES"] or [mh ^"HOME CARE SERVICES"] or [mh ^"HEALTH SERVICES FOR PEOPLE WITH DISABILITIES"] or [mh ^"MENTAL HEALTH SERVICES"] or [mh ^"NURSING SERVICES"] or [mh "HEALTH PERSONNEL"]) and ([mh "SOCIAL WORK"] or [mh ^"SOCIAL WORK, PSYCHIATRIC"] or [mh ^"SOCIAL WORKERS"] or [mh ^"SOCIAL SUPPORT"])
#42	([mh ^"HEALTH SERVICES"] or [mh ^"CHILD HEALTH SERVICES"] or [mh ^"ADOLESCENT HEALTH SERVICES"] or [mh ^"COMMUNITY HEALTH SERVICES"] or [mh ^"HOME CARE SERVICES"] or [mh ^"HEALTH SERVICES FOR PEOPLE WITH DISABILITIES"] or [mh ^"MENTAL HEALTH SERVICES"] or [mh ^"NURSING SERVICES"] or [mh "HEALTH PERSONNEL"]) and ([mh ^"EDUCATION"] or [mh "EDUCATION, SPECIAL"] or [mh ^"SCHOOLS"] or [mh ^"SCHOOL HEALTH SERVICES"] or [mh ^"SCHOOLS, NURSERY"] or [mh NURSERY] or [mh ^"CHILD DAY CARE CENTERS"] or [mh ^"UNIVERSITIES"] or [mh ^"TEACHING"] or [mh ^"REMEDIAL TEACHING"] or [mh ^"SCHOOL TEACHERS"])
#43	([mh "SOCIAL WORK"] or [mh ^"SOCIAL WORK, PSYCHIATRIC"] or [mh ^"SOCIAL WORKERS"] or [mh ^"SOCIAL SUPPORT"]) and ([mh ^"EDUCATION"] or [mh "EDUCATION, SPECIAL"] or [mh ^"SCHOOLS"] or [mh ^"SCHOOL HEALTH SERVICES"] or [mh ^"SCHOOLS, NURSERY"] or [mh NURSERY] or [mh ^"CHILD DAY CARE CENTERS"] or [mh ^"UNIVERSITIES"] or [mh ^"TEACHING"] or [mh ^"REMEDIAL TEACHING"] or [mh ^"SCHOOL TEACHERS"])
#44	#41 or #42 or #43
#45	((health* or NHS or clinical or clinician* or medical or medic or medics or physician* or consultant* or nurse* or general practitioner* or GP or GPs or occupational therapist* or OT or OTs or allied health professional* or AHP or AHPs or ((speech or language) near/3 therapist*) or SLT or SLTs) near/5 social* near/5 (care or service* or

#	Searches
	department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering* or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#46	((health* or NHS or clinical or clinician* or medical or medic or medics or physician* or consultant* or nurse* or general practitioner* or GP or GPs or occupational therapist* or OT or OTs or allied health professional* or AHP or AHPs or ((speech or language) near/3 therapist*) or SLT or SLTs) near/5 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*) near/5 (care or service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering* or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#47	(social* near/5 (educat* or school* or teach* or headmaster* or headmistress* or SENCO or SENCOs or DfE*) near/5 (care or service* or department* or institution* or organisation* or organization* or sector* or agenc* or provider* or policy or policies or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering* or network* or inter or multi or joint* or across or share* or sharing or together or communicat* or barrier* or facilitat* or deliver*)):ti,ab
#48	#45 or #46 or #47
#49	[mh ^"STATE MEDICINE"/og]
#50	[mh ^"CHILD HEALTH SERVICES"/og]
#51	[mh ^"ADOLESCENT HEALTH SERVICES"/og]
#52	[mh ^"EDUCATION"/og]
#53	[mh "EDUCATION, SPECIAL"/og]
#54	[mh "SOCIAL WORK"/og]
#55	#49 or #50 or #51 or #52 or #53 or #54
#56	[mh ^"TERMINALLY ILL"]
#57	[mh ^"ADVANCE CARE PLANNING"]
#58	[mh ^"ADVANCE DIRECTIVES"]
#59	[mh ^"LIVING WILLS"]
#60	[mh ^"RESUSCITATION ORDERS"]
#61	[mh ^"TERMINAL CARE"]
#62	[mh ^"PALLIATIVE CARE"]
#63	[mh ^"HOSPICE CARE"]
#64	((terminal* or advance* or incurable or "life limit*" or "life threaten*" or "life shorten*") near/3 (ill* or disease* or condition*)):ti,ab
#65	(end near/3 life):ti,ab
#66	dying:ti,ab
#67	((approach* or close* or near* or imminent* or impending) near/3 death):ti,ab
#68	("last year of life" or LYOL or "life* end"):ti,ab
#69	((advanced or late or last or end or final or terminal) near/1 (phase* or stage*)):ti,ab
#70	"advance* care plan*":ti,ab
#71	"advance* directive*":ti,ab
#72	"living will*":ti,ab
#73	(resuscitat* near/3 (policies or policy or order* or decision* or withhold*)):ti,ab
#74	(terminal* near/3 (care* or caring)):ti,ab
#75	palliat*:ti,ab
#76	hospice*:ti,ab
#77	#56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72 or #73 or #74 or #75 or #76
#78	[mh ^"ADVANCE CARE PLANNING"/og]
#79	[mh ^"TERMINAL CARE"/og]
#80	[mh ^"PALLIATIVE CARE"/og]
#81	[mh ^"HOSPICE CARE"/og]
#82	#78 or #79 or #80 or #81
#83	(palliat* near/3 service* near/5 (involv* or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering* or network* or inter* or multi* or joint* or across or share* or sharing or together or communicat*)):ti,ab
#84	((charit* or "third sector" or "non-government* organi*" or NGO* or "non-profit* organi*" or "not-for-profit organi*" or volunt* or communit* or "social enterprise" or VCSE) near/5 (involv* or collaborat* or coordinat* or co-ordinat* or cooperat* or co-operat* or integrat* or partnership* or partnering* or network* or inter* or multi* or joint* or across or share* or sharing or together or communicat*)):ti,ab
#85	#27 and (#40 or #44 or #48 or #55) and #77
#86	#27 and #82
#87	#12 and #83
#88	#27 and #77 and #84
#89	#85 or #86 or #87 or #88
#90	#85 or #86 or #87 or #88 with Cochrane Library publication date Between Jan 2000 and Jun 2020, in Cochrane Reviews
#91	#85 or #86 or #87 or #88 with Publication Year from 2000 to 2020, in Trials

1 Database: Database of Abstracts of Reviews of Effects (DARE)

2 Date of last search: 19/06/2020

#	Searches
1	MeSH DESCRIPTOR ADOLESCENT IN DARE
2	MeSH DESCRIPTOR MINORS IN DARE
3	((adolescen* or teen* or youth* or young or juvenile* or minors or highschool*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
4	MeSH DESCRIPTOR CHILD EXPLODE ALL TREES IN DARE
5	((child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
6	MeSH DESCRIPTOR INFANT EXPLODE ALL TREES IN DARE
7	((infan* or neonat* or newborn* or baby or babies)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
8	MeSH DESCRIPTOR PEDIATRICS EXPLODE ALL TREES IN DARE
9	((pediatric* or paediatric*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
10	MeSH DESCRIPTOR YOUNG ADULT IN DARE
11	(("young* adult*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11
13	MeSH DESCRIPTOR DISABLED PERSONS EXPLODE ALL TREES IN DARE
14	MeSH DESCRIPTOR MENTAL DISORDERS EXPLODE ALL TREES IN DARE
15	MeSH DESCRIPTOR COMMUNICATION DISORDERS EXPLODE ALL TREES IN DARE
16	MeSH DESCRIPTOR INTELLECTUAL DISABILITY EXPLODE ALL TREES IN DARE
17	((disable* or disabilit* or handicap* or retard* or disorder* or impair* or condition* or difficulty or difficulties or deficit* or dysfunct*:TI) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
18	(((((sever* or complex* or special or high) adj3 need*))) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
19	#13 OR #14 OR #15 OR #16 OR #17 OR #18
20	#12 AND #19
21	MeSH DESCRIPTOR DISABLED CHILDREN IN DARE
22	((CSHCN)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
23	((("Education Health" adj2 "Care plan*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
24	(("EHC plan*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
25	((EHCP*)) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
26	#20 OR #21 OR #22 OR #23 OR #24 OR #25
27	MeSH DESCRIPTOR TERMINALLY ILL IN DARE
28	MeSH DESCRIPTOR ADVANCE CARE PLANNING IN DARE
29	MeSH DESCRIPTOR ADVANCE DIRECTIVES IN DARE
30	MeSH DESCRIPTOR LIVING WILLS IN DARE
31	MeSH DESCRIPTOR RESUSCITATION ORDERS IN DARE
32	MeSH DESCRIPTOR TERMINAL CARE IN DARE
33	MeSH DESCRIPTOR PALLIATIVE CARE IN DARE
34	MeSH DESCRIPTOR HOSPICE CARE IN DARE
35	((("terminal ill*" or "terminal* ill" or "terminal disease*" or "terminal condition*" or "life limit*" or "life threaten*" or "life shorten*" or "end of life" or "advance care plan*" or "advance directive*" or "living will*" or "terminal care" or palliat* or hospice*")) and ((Systematic review:ZDT and Bibliographic:ZPS) OR (Systematic review:ZDT and Abstract:ZPS))
36	#27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35
37	#26 AND #36

3

4 Database: Health Technology Abstracts (HTA)

5 Date of last search: 19/06/2020

#	Searches
1	MeSH DESCRIPTOR ADOLESCENT IN HTA
2	MeSH DESCRIPTOR MINORS IN HTA
3	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*) IN HTA
4	MeSH DESCRIPTOR CHILD EXPLODE ALL TREES IN HTA
5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*) IN HTA
6	MeSH DESCRIPTOR INFANT EXPLODE ALL TREES IN HTA
7	(infan* or neonat* or newborn* or baby or babies) IN HTA
8	MeSH DESCRIPTOR PEDIATRICS EXPLODE ALL TREES IN HTA
9	(pediatric* or paediatric*) IN HTA
10	MeSH DESCRIPTOR YOUNG ADULT IN HTA
11	("young* adult*") IN HTA

#	Searches
12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11
13	MeSH DESCRIPTOR DISABLED PERSONS EXPLODE ALL TREES IN HTA
14	MeSH DESCRIPTOR MENTAL DISORDERS EXPLODE ALL TREES IN HTA
15	MeSH DESCRIPTOR COMMUNICATION DISORDERS EXPLODE ALL TREES IN HTA
16	MeSH DESCRIPTOR INTELLECTUAL DISABILITY EXPLODE ALL TREES IN HTA
17	(disable* or disabilit* or handicap* or retard* or disorder* or impair* or condition* or difficulty or difficulties or deficit* or dysfunc*):TI IN HTA
18	((sever* or complex* or special or high) adj3 need*) IN HTA
19	#13 OR #14 OR #15 OR #16 OR #17 OR #18
20	#12 AND #19
21	MeSH DESCRIPTOR DISABLED CHILDREN IN HTA
22	(CSHCN) IN HTA
23	("Education Health" adj2 "Care plan*")) IN HTA
24	("EHC plan*") IN HTA
25	(EHCP*) IN HTA
26	#20 OR #21 OR #22 OR #23 OR #24 OR #25
27	MeSH DESCRIPTOR TERMINALLY ILL IN HTA
28	MeSH DESCRIPTOR ADVANCE CARE PLANNING IN HTA
29	MeSH DESCRIPTOR ADVANCE DIRECTIVES IN HTA
30	MeSH DESCRIPTOR LIVING WILLS IN HTA
31	MeSH DESCRIPTOR RESUSCITATION ORDERS IN HTA
32	MeSH DESCRIPTOR TERMINAL CARE IN HTA
33	MeSH DESCRIPTOR PALLIATIVE CARE IN HTA
34	MeSH DESCRIPTOR HOSPICE CARE IN HTA
35	("terminal ill*" or "terminal* ill" or "terminal disease*" or "terminal condition*" or "life limit*" or "life threaten*" or "life shorten*" or "end of life" or "advance care plan*" or "advance directive*" or "living will*" or "terminal care" or palliat* or hospice*) IN HTA
36	#27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35
37	#26 AND #36

1

2 **Databases: Applied Social Sciences Index & Abstracts (ASSIA); Social Services**
3 **Abstracts; Sociological Abstracts; and ERIC (Education Resources Information**
4 **Centre)**

5 **Date of last search: 19/06/2020**

#	Searches
1	AB, TI((adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p?ediatric* OR "young* adult?")
2	TI(disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunc* OR ((sever* OR complex* OR special OR high) NEAR/3 need?) OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?)
3	AB, TI((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) AB, TI(adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p?ediatric* OR "young* adult?")
4	TI((interinstitution* OR multiinstitution* OR jointinstitution* OR interorgani?ation* OR multiorgani?ation* OR jointorgani?ation* OR intersector* OR multisector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprovider* OR multiprovider* OR jointprovider* OR interstakeholder* OR multistakeholder* OR jointstakeholder* OR interprofession* OR multiprofession* OR jointprofession* OR service? OR collaborat* OR "care coordinat*" OR "coordinat* care" OR partnership? OR partnering OR network*)
5	TI(((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social*) OR ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) OR (social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)))
6	TI(("terminal ill*" or "terminal* ill" or "terminal disease*" or "terminal condition*" or "life limit*" or "life threaten*" or "life shorten*" or "end of life" or "advance care plan*" or "advance directive*" or "living will*" or "terminal care" or palliat* or hospice*)
7	1 AND 2 AND 3 AND 6 Additional limits - Date: From January 2000 to June 2020
8	1 AND 2 AND 4 AND 6 Additional limits - Date: From January 2000 to June 2020
9	1 AND 2 AND 5 AND 6 Additional limits - Date: From January 2000 to June 2020
10	7 OR 8 OR 9

1

2 Database: British Education Index

3 Date of last search: 19/06/2020

#	Searches
1	TX("terminal ill*" or "terminal* ill" or "terminal disease*" or "terminal condition*" or "life limit*" or "life threaten*" or "life shorten*" or "end of life" or "advance care plan*" or "advance directive*" or "living will*" or "terminal care" or palliat* or hospice*) AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunc* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND TI (interinstitution* OR multiinstitution* OR jointinstitution* OR interorgani?ation* OR multiorgani?ation* OR jointorgani?ation* OR intersector* OR multisector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprovider* OR multiprovider* OR jointprovider* OR interstakeholder* OR multistakeholder* OR jointstakeholder* OR interprofession* OR multiprofession* OR jointprofession* OR service? OR collaborat* OR "care coordinat*" OR "care co-ordinat*" OR "coordinat* care" OR "coordinat* care" OR partnership? OR partnering OR network*) Limiters - Publication Date: 20000101-20200631
2	TX("terminal ill*" or "terminal* ill" or "terminal disease*" or "terminal condition*" or "life limit*" or "life threaten*" or "life shorten*" or "end of life" or "advance care plan*" or "advance directive*" or "living will*" or "terminal care" or palliat* or hospice*) AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunc* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND TI (((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social*) OR ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) OR (social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)))) Limiters - Publication Date: 20000101-20200631
3	1 or 2

4

5 Database: CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature)

7 Date of last search: 19/06/2020

#	Searches
1	TX ("terminal ill*" or "terminal* ill" or "terminal disease*" or "terminal condition*" or "life limit*" or "life threaten*" or "life shorten*" or "end of life" or "advance care plan*" or "advance directive*" or "living will*" or "terminal care" or palliat* or hospice*) AND TI (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TX (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunc* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND TI (interinstitution* OR multiinstitution* OR jointinstitution* OR interorgani?ation* OR multiorgani?ation* OR jointorgani?ation* OR intersector* OR multisector* OR jointsector* OR interagenc* OR multiagenc* OR jointagenc* OR interprovider* OR multiprovider* OR jointprovider* OR interstakeholder* OR multistakeholder* OR jointstakeholder* OR interprofession* OR multiprofession* OR jointprofession* OR service? OR collaborat* OR "care coordinat*" OR "care co-ordinat*" OR "coordinat* care" OR "coordinat* care" OR partnership? OR partnering OR network*) Limiters - Publication Date: 2000-2020
2	TX ("terminal ill*" or "terminal* ill" or "terminal disease*" or "terminal condition*" or "life limit*" or "life threaten*" or "life shorten*" or "end of life" or "advance care plan*" or "advance directive*" or "living will*" or "terminal care" or palliat* or hospice*) AND TX (adolescen* OR teen* OR youth* OR young OR juvenile? OR minors OR highschool* OR child* OR schoolchild* OR "school age" OR "school aged" OR preschool* OR toddler* OR kid? OR kindergar* OR boy? OR girl? OR infan* OR neonat* OR newborn* OR baby OR babies OR p#ediatric* OR "young* adult?") AND TI (disable? OR disabilit* OR handicap* OR retard* OR disorder? OR impair* OR condition? OR difficulty OR difficulties OR deficit? OR dysfunc* OR "sever* need?" OR "complex* need?" OR "special need?" OR "special educat* need?" OR "high need?" OR SHCN OR CSHCN OR "Education Health and Care plan?" OR "EHC plan?" OR EHCP?) AND TI (((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND social*) OR ((health* OR NHS OR clinical OR clinician? OR medical OR medic? OR physician? OR consultant? OR nurse? OR "general practitioner?" OR GP? OR "occupational therapist?" OR OT? OR "allied health professional?" OR AHP? OR "speech therapist?" OR "language therapist?" OR SLT?) AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?)) OR (social* AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?))))

#	Searches
	AND (educat* OR school* OR teach* OR headmaster? OR headmistress* OR SENCO? OR DfE?))) Limiters - Publication Date: 2000- 2020
3	1 or 2

1

2 Database: Social Sciences Citation Index (SSCI)

3 Date of last search: 19/06/2020

#	Searches
# 1	TOPIC: ((adolescen* or teen* or youth* or young or juvenile\$ or minors or highschool*)) Indexes=SSCI Timespan=2000-2020
# 2	TOPIC: ((child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid\$ or kindergar* or boy\$ or girl\$)) Indexes=SSCI Timespan=2000-2020
# 3	TOPIC: ((infan* or neonat* or newborn* or baby or babies)) Indexes=SSCI Timespan=2000-2020
# 4	TOPIC: (p\$ediatric*) Indexes=SSCI Timespan=2000-2020
# 5	TOPIC: ("young* adult\$") Indexes=SSCI Timespan=2000-2020
# 6	#5 OR #4 OR #3 OR #2 OR #1 Indexes=SSCI Timespan=2000-2020
# 7	TITLE: ((disable\$ or disabilit* or handicap* or retard* or disorder\$ or impair* or condition\$ or difficulty or difficulties or deficit\$ or dysfunct*)) Indexes=SSCI Timespan=2000-2020
# 8	TOPIC: (((sever* or complex* or special or high) near/3 need\$)) Indexes=SSCI Timespan=2000-2020
# 9	TOPIC: (SHCN) Indexes=SSCI Timespan=2000-2020
# 10	#9 OR #8 OR #7 Indexes=SSCI Timespan=2000-2020
# 11	#10 AND #6 Indexes=SSCI Timespan=2000-2020
# 12	TOPIC: (CSHCN) Indexes=SSCI Timespan=2000-2020
# 13	TOPIC: ("Education Health and Care plan\$") Indexes=SSCI Timespan=2000-2020
# 14	TOPIC: ("EHC plan\$") Indexes=SSCI Timespan=2000-2020
# 15	TOPIC: (EHCP\$) Indexes=SSCI Timespan=2000-2020
# 16	#15 OR #14 OR #13 OR #12 OR #11 Indexes=SSCI Timespan=2000-2020
# 17	TOPIC: (((health or healthcare or NHS or clinical or medical or medic or medics or nurse or nurses) near/5 social)) Indexes=SSCI Timespan=2000-2020
# 18	TOPIC: ((health or healthcare or NHS or clinical or medical or medic or medics or nurse or nurses) near/5 (education or educating or educator or educators or school or schools or teach or teaching or teachers)) Indexes=SSCI Timespan=2000-2020
# 19	TOPIC: ((social near/5 (education or educating or educator or educators or school or schools or teach or teaching or teachers))) Indexes=SSCI Timespan=2000-2020
# 20	#19 OR #18 OR #17 Indexes=SSCI Timespan=2000-2020
# 21	TOPIC: ("terminal ill*" or "terminal* ill" or "terminal disease*" or "terminal condition*" or "life limit*" or "life threaten*" or "life shorten*" or "end of life" or "advance care plan*" or "advance directive*" or "living will*" or "terminal care" or palliat* or hospice*) Indexes=SSCI Timespan=2000-2020
# 22	#21 AND #20 AND #16 Indexes=SSCI Timespan=2000-2020

4

5 Database: Social Care Online

6 Date of last search: 19/06/2020

#	Searches
	Title: disabled or disability or disabilities or handicap or retard or disorder or impaired or impairment or difficulty or difficulties or deficit or dysfunction or "special need" or "complex need"
	AND All fields: child or children or schoolchild or schoolchildren or "school age" or "school aged" or preschool or toddler or kid or kindergarden or boy or girl or infant or neonate or newborn or baby or babies or paediatric or paediatric or "young people" or "young adults"
	AND Title: "terminal ill" or "terminal disease" or "terminal condition" or "life limiting" or "life threatening" or "life shortening" or "end of life" or "advance care plan" or "advance directive" or "living will" or "terminal care" or palliative or hospice
	AND PublicationYear: 2000 2020

7

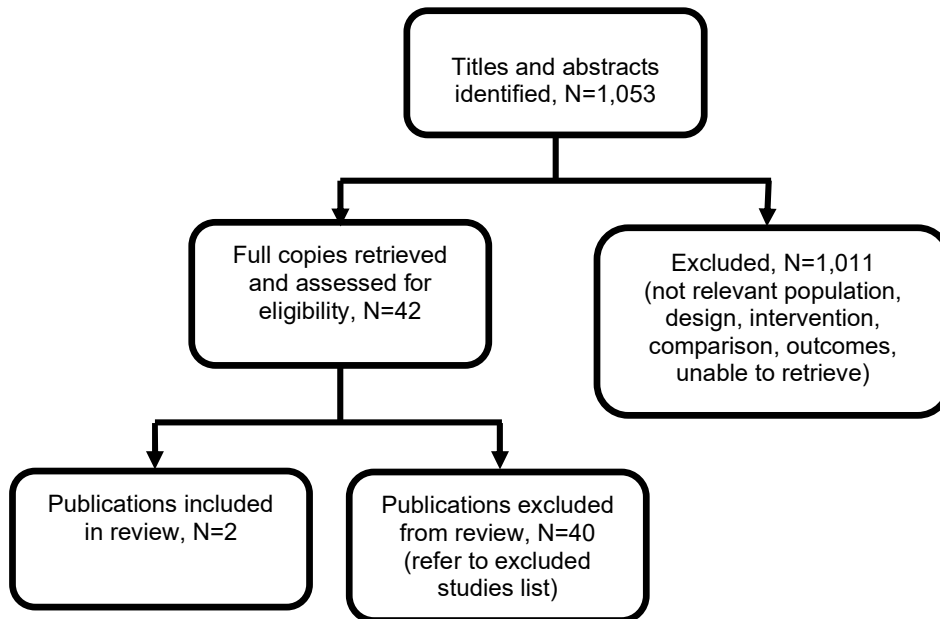
8

1 Appendix C – Effectiveness evidence study selection

2 **Study selection for review question: What combined health, social care and**
3 **education service delivery arrangements can best provide for the needs of**
4 **disabled children and young people with severe complex needs on a palliative**
5 **or advance care plan, and for the needs of their families and carers?**

6 **Figure 1: Study selection flow chart**

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1 Appendix D – Effectiveness evidence

2 **Evidence tables for review question: What combined health, social care and education service delivery arrangements can**
3 **best provide for the needs of disabled children and young people with severe complex needs on a palliative or advance**
4 **care plan, and for the needs of their families and carers?**

5 **Table 4: Evidence tables**

Study details	Results and risk of bias assessment using EPOC RoB tool for before and after studies
<p>Full citation Hays, Ross M., Valentine, Jeanette, Haynes, Gerri, Geyer, J. Russel, Villareale, Nanci, McKinstry, Beth, Varni, James W., Churchill, Shervin S., The Seattle Pediatric Palliative Care Project: effects on family satisfaction and health-related quality of life, Journal of Palliative Medicine, 9, 716-28, 2006</p> <p>Ref Id 1268111</p> <p>Country/ies where the study was carried out USA</p> <p>Study type Before and after study</p> <p>Study dates 1999-2001</p> <p>Inclusion criteria Children and young people aged 0-21 years with a severe illness that may result in death within 2 years, resident of Washington State and insured with one of the health plans participating in the Seattle Paediatric Palliative Care Project.</p> <p>Exclusion criteria</p>	<p>Results</p> <p>Coordination of care and management of care processes: Individual case management, communication/referral between providers, shared decision making, multidisciplinary teams</p> <p>Quality of life: Physical (Reported by parents; measured by PedsQL; scale of 0 to 100; higher scores indicate better quality of life) After SPPCP: M=54.21, N=10 versus Before SPPCP: M=40.82, N=10; MD=13.39, p-value=0.148</p> <p>Quality of life: Emotional (Reported by parents; measured by PedsQL; scale of 0 to 100; higher scores indicate better quality of life) After SPPCP: M=62.73, N=18 versus Before SPPCP: M=52.52, N=18; MD=10.21, p-value=0.021</p> <p>Quality of life: Social (Reported by parents; measured by PedsQL; scale of 0 to 100; higher scores indicate better quality of life) After SPPCP: M=62.81, N=15 versus Before SPPCP: M=64.00, N=15; MD=-1.19, p-value=0.847</p> <p>Quality of life: School (Reported by parents; measured by</p>

Study details	Results and risk of bias assessment using EPOC RoB tool for before and after studies
<p>No additional criteria reported</p> <p>Patient characteristics N=41 Age at enrolment into programme (mean; range): 11.3 years; 3 months to 21 years Gender: n=19 (46%) male; n=22 (54%) female Ethnicity: n=33 (80%) Caucasian Diagnosis: n=14 (34%) cancer; n=10 (24%) progressive neurologic disease; n=8 (20%) central nervous system damage; n=4 (10%) multiple congenital anomalies; n=2 (5%) metabolic disorders; n=2 (5%) cardiac disease; n=1 (2%) respiratory (cystic fibrosis)</p> <p>Interventions Seattle Pediatric Palliative Care Project (SPPCP): Aimed to deliver curative and comfort family-centred palliative care. The project team included two physician principal investigators, two advanced practice nurses, social worker, benefits coordinator and case managers from participating insurance plans. The program has three main components: 1) clinical-decision making, supported by the Decision-making Tool (DMT), focusing on medical indications, patient/family preference, quality of life and context; 2) provider education; and 3) flexible administration of benefits and co-case management by participating health plans and a nurse to support implementation of needs and preferences identified in the DMT. The DMT was shared with families and insurance plans and was available to any health providers treating the patients.</p> <p>Follow-up Data was collected at baseline (enrolment) and 3 months after enrolment.</p>	<p>PedsQL; scale of 0 to 100; higher scores indicate better quality of life) After SPPCP: M=65.00, N=6 versus Before SPPCP: M=45.85, N=6; MD=19.17*, p-value=0.284</p> <p>Quality of life: Psychosocial summary score (Reported by parents; measured by PedsQL; scale of 0 to 100; higher scores indicate better quality of life) After SPPCP: M=62.68, N=15 versus Before SPPCP: M=58.41, N=15; MD=4.28, p-value=0.404</p> <p>Quality of life: Total scale score (Reported by parents; measured by PedsQL; scale of 0 to 100; higher scores indicate better quality of life) After SPPCP: M=60.50, N=16 versus Before SPPCP: M=51.95, N=16; MD=8.55, p-value=0.118</p> <p>Satisfaction with palliative and/or advance care: Parents satisfaction with overall care the child received (scale of 1 [very unsatisfied] to 5 [very satisfied]) After SPPCP: M=4.40, N=20 versus Before SPPCP: M=4.20, N=20; MD=0.20, p-value=0.464</p> <p>1. Random sequence generation High risk, controlled before-after study - no randomisation</p> <p>2. Allocation concealment High risk, controlled before-after study - no randomisation</p> <p>3. Baseline outcome measurements similar Low risk, one baseline measurement was taken at enrolment</p> <p>4. Baseline characteristics similar</p>

Study details	Results and risk of bias assessment using EPOC RoB tool for before and after studies
	<p>Low risk, only one baseline measurement was taken</p> <p>5. Incomplete outcome data High risk matched before and after data was only available for a maximum of n=22 (54%) depending on outcome</p> <p>6. Knowledge of the allocated interventions adequately prevented during the study High risk, outcomes were not assessed blindly</p> <p>7. Protection against contamination Low risk, controlled before-after study so control group was pre-intervention</p> <p>8. Selective outcome reporting Low risk, all outcomes reported sufficiently</p> <p>9. Other risks of bias High risk, no separate control group (before-after-study)</p> <p>Source of funding Not industry funded</p> <p>Other information Evidence for the population is indirect as children with cancer and cardiac disease (accounting for 39% of the sample) are unlikely to have severe complex needs in all three areas.</p>
<p>Full citation Horrocks, S., Somerset, M., Salisbury, C., Do children with non-malignant life-threatening conditions receive effective palliative care? A pragmatic evaluation of a local service, Palliative Medicine, 16, 410-416, 2002</p> <p>Ref Id</p>	<p>Results</p> <p>Coordination of care and management of care processes: Communication/referral between providers, shared care, multidisciplinary teams Extent to which needs are met: Unmet information needs</p>

Study details	Results and risk of bias assessment using EPOC RoB tool for before and after studies
<p>344555</p> <p>Country/ies where the study was carried out UK</p> <p>Study type Before and after study</p> <p>Study dates October 1998-Not reported</p> <p>Inclusion criteria Children (with life-limiting genetic, metabolic and degenerative disorders) referred to the Avon Lifetime Service.</p> <p>Exclusion criteria Fostered children and children considered close to death.</p> <p>Patient characteristics N=16* Age (range): 5 months to 17 years Gender: n=10 (62.5%) male; n=6 (37.5%) female Diagnosis: n=6 (37.5%) degenerative; n=4 (25%) neurological; n=2 (12.5%) severe congenital anomaly; n=2 (12.5%) circulatory; n=1 (6.3%) metabolic *Follow-up data was available for an additional 13 children but these data have not been extracted as no comparative data was available</p> <p>Interventions Avon Lifetime Service (ALS): Community nursing and psychology services for children with life-limiting genetic, metabolic and degenerative disorder and their families. Service staffed by community paediatric nurses and child psychologists but included coordinating services and liaising with schools and social services. Aimed to reduce stress, improve psychological wellbeing, support and educate families to feel confident and competent</p>	<p>After ALS: 5/16 versus Before ALS: 10/16</p> <p>Extent to which needs are met: Unmet equipment needs After ALS: 13/16 versus Before ALS: 11/16</p> <p>Extent to which needs are met: Unmet respite needs (at home) After ALS: 5/16 versus Before ALS: 7/16</p> <p>Extent to which needs are met: Unmet respite needs (outside home) After ALS: 7/16 versus Before ALS 6/16</p> <p>Extent to which needs are met: Families providing nursing care daily After ALS: 9/16 versus Before ALS: 12/16</p> <p>Extent to which needs are met: Families reporting difficulties with nursing care After ALS: 6/16 versus Before ALS: 11/16</p> <p>1. Random sequence generation High risk, controlled before-after study - no randomisation</p> <p>2. Allocation concealment High risk, controlled before-after study - no randomisation</p> <p>3. Baseline outcome measurements similar Low risk, one baseline measurement was taken at enrolment</p> <p>4. Baseline characteristics similar Low risk, only one baseline measurement was taken</p>

Study details	Results and risk of bias assessment using EPOC RoB tool for before and after studies
<p>caring for their child, reduce hospital attendance and admission, educate and train other carers, assist with networking to reduce isolation and enable children with terminal illnesses to receive care and die in an environment of their (and their carers) choice.</p> <p>Follow-up Data was collected at baseline (enrolment) and 6 months after enrolment.</p>	<p>5. Incomplete outcome data Low risk, no missing outcome data</p> <p>6. Knowledge of the allocated interventions adequately prevented during the study High risk, outcomes were not assessed blindly</p> <p>7. Protection against contamination Low risk, controlled before-after study so control group was pre-intervention</p> <p>8. Selective outcome reporting Low risk, all outcomes reported sufficiently</p> <p>9. Other risks of bias High risk, no separate control group (before-after-study)</p> <p>Source of funding Not industry funded</p> <p>Other information</p>

1 ALS: Avon Lifetime Service; DMT: Decision-making Tool; EPOC: Effective Practice and Organisation of Care; M: mean; MD: mean difference; N: number of participants;
 2 PedsQL: Pediatric Quality of Life Inventory; RoB: risk of bias; SD: standard deviation; SPPCP: Seattle Pediatric Palliative Care Project

3

4 **Appendix E – Forest plots**

5 **Forest plots for review question: What combined health, social care and**
6 **education service delivery arrangements can best provide for the needs of**
7 **disabled children and young people with severe complex needs on a palliative**
8 **or advance care plan, and for the needs of their families and carers?**

9 No meta-analysis was conducted for this review question and so there are no forest plots.

1 Appendix F – GRADE tables

2 **GRADE tables for review question: What combined health, social care and education service delivery arrangements can best**
3 **provide for the needs of disabled children and young people with severe complex needs on a palliative or advance care**
4 **plan, and for the needs of their families and carers?**

5 **Table 5: Evidence profile for comparison 1: After SPPCP versus before SPPCP (Practice and service delivery models: Coordination of**
6 **care and management of care processes: Individual case management/communication/referral between providers/shared**
7 **decision making/multidisciplinary teams)**

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	After SPPCP	Before SPPCP	Relative (95% CI)	Absolute		
Quality of life: Physical (Reported by parents; measured by PedsQL) (range of scores: 0-100; Better indicated by higher values)												
1 (Hays 2006)	observational studies	very serious ¹	no serious inconsistency	serious ²	serious ³	none	10	10	-	MD 13.39 higher (4.01 lower to 30.79 higher)	VERY LOW	CRITICAL
Quality of life: Emotional (Reported by parents; measured by PedsQL) (range of scores: 0-100; Better indicated by higher values)												
1 (Hays 2006)	observational studies	very serious ¹	no serious inconsistency	serious ²	serious ³	none	18	18	-	MD 10.21 higher (1.94 to 18.48 higher)	VERY LOW	CRITICAL
Quality of life: Social (Reported by parents; measured by PedsQL) (range of scores: 0-100; Better indicated by higher values)												
1 (Hays 2006)	observational studies	serious ¹	no serious inconsistency	serious ²	very serious ⁴	none	15	15	-	MD 1.19 lower (13.17 lower to 10.79 higher)	VERY LOW	CRITICAL
Quality of life: School (Reported by parents; measured by PedsQL) (range of scores: 0-100; Better indicated by higher values)												
1 (Hays 2006)	observational studies	very serious ¹	no serious inconsistency	serious ²	serious ³	none	6	6	-	MD 19.15 higher (14.21 lower to 52.51 higher)	VERY LOW	CRITICAL
Quality of life: Psychosocial summary score (Reported by parents; measured by PedsQL) (range of scores: 0-100; Better indicated by higher values)												
1 (Hays 2006)	observational studies	very serious ¹	no serious inconsistency	serious ²	serious ³	none	15	15	-	MD 4.27 higher (5.63 lower to	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	After SPPCP	Before SPPCP	Relative (95% CI)	Absolute		
											14.17 higher)	
Quality of life: Total scale score (Reported by parents; measured by PedsQL) (range of scores: 0-100; Better indicated by higher values)												
1 (Hays 2006)	observational studies	very serious ¹	no serious inconsistency	serious ²	serious ³	none	16	16	-	MD 8.55 higher (1.86 lower to 18.96 higher)	VERY LOW	CRITICAL
Satisfaction with palliative and/or advance care: Parents' satisfaction with overall care the child received (range of scores: 1-5; Better indicated by higher values)												
1 (Hays 2006)	observational studies	very serious ¹	no serious inconsistency	serious ²	serious ³	none	20	20	-	MD 0.2 higher (0.33 lower to 0.73 higher)	VERY LOW	IMPORTANT

- 1 *CI: confidence interval; EPOC: Effective Practice and Organisation of Care; MD: mean difference; MID: minimally important difference; PedsQL: Pediatric Quality of Life*
2 *Inventory; RoB: risk of bias; SD: standard deviation; SPPCP: Seattle Pediatric Palliative Care Project*
3 ¹ *Very serious risk of bias in the evidence contributing to the outcomes as per EPOC RoB tool for before and after studies*
4 ² *Population is indirect*
5 ³ *95% CI crosses 1 MID (0.5x control group SD, for 'quality of life: physical' = 9.93; for 'quality of life: emotional' = 6.33; for 'quality of life: school' = 14.74; for 'quality of life: psychosocial summary score' = 6.92; for 'quality of life: total scale score' = 7.51; for 'satisfaction with overall care' = 0.43)*
6 ⁴ *95% CI crosses 2 MIDs (0.5x control group SD, for 'quality of life: social' = 8.37)*
7

8 **Table 6: Evidence profile for comparison 2: After ALS versus before ALS (Practice and service delivery models: Coordination of care**
9 **and management of care processes: Communication/referral between providers/shared care/multidisciplinary teams)**

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	After ALS	Before ALS	Relative (95% CI)	Absolute		
Extent to which needs are met: Unmet information needs												
1 (Horrocks 2002)	observational studies	very serious ¹	no serious inconsistency	no serious indirectness	serious ²	none	5/16 (31.3%)	10/16 (62.5%)	RR 0.5 (0.22 to 1.14)	312 fewer per 1000 (from 488 fewer to 87 more)	VERY LOW	CRITICAL
Extent to which needs are met: Unmet equipment needs												
1 (Horrocks 2002)	observational studies	very serious ¹	no serious inconsistency	no serious indirectness	very serious ³	none	13/16 (81.3%)	11/16 (68.8%)	RR 1.18 (0.79 to 1.71)	124 more per 1000 (from 144 more to 144 more)	VERY LOW	CRITICAL

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	After ALS	Before ALS	Relative (95% CI)	Absolute		
									1.77)	fewer to 529 more)		
Extent to which needs are met: Unmet respite needs (at home)												
1 (Horrocks 2002)	observational studies	very serious ¹	no serious inconsistency	no serious indirectness	very serious ³	none	5/16 (31.3%)	7/16 (43.8%)	RR 0.71 (0.29 to 1.78)	127 fewer per 1000 (from 311 fewer to 341 more)	VERY LOW	CRITICAL
Extent to which needs are met: Unmet respite needs (outside home)												
1 (Horrocks 2002)	observational studies	very serious ¹	no serious inconsistency	no serious indirectness	very serious ³	none	7/16 (43.8%)	6/16 (37.5%)	RR 1.17 (0.5 to 2.71)	64 more per 1000 (from 188 fewer to 641 more)	VERY LOW	CRITICAL
Extent to which needs are met: Families providing nursing care												
1 (Horrocks 2002)	observational studies	very serious ¹	no serious inconsistency	no serious indirectness	very serious ³	none	9/16 (56.3%)	12/16 (75%)	RR 0.75 (0.45 to 1.26)	188 fewer per 1000 (from 413 fewer to 195 more)	VERY LOW	CRITICAL
Extent to which needs are met: Families reporting difficulties with nursing care												
1 (Horrocks 2002)	observational studies	very serious ¹	no serious inconsistency	no serious indirectness	serious ²	none	6/16 (37.5%)	11/16 (68.8%)	RR 0.55 (0.27 to 1.11)	309 fewer per 1000 (from 502 fewer to 76 more)	VERY LOW	CRITICAL

- 1 ALS: Avon Lifetime Service; CI: confidence interval; EPOC: Effective Practice and Organisation of Care; MID: minimally important difference; RoB: risk of bias; RR: risk ratio
2 ¹ Very serious risk of bias in the evidence contributing to the outcomes as per EPOC RoB tool for before and after studies
3 ² 95% CI crosses 1 MID
4 ³ 95% CI crosses 2 MIDs

1 **Appendix G – Economic evidence study selection**

2 **Economic evidence study selection for review question: What combined health,**
3 **social care and education service delivery arrangements can best provide for**
4 **the needs of disabled children and young people with severe complex needs**
5 **on a palliative or advance care plan, and for the needs of their families and**
6 **carers?**

7 One global search was undertaken – please see Supplement B for details on study selection.

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1 **Appendix H – Economic evidence tables**

2 **Economic evidence tables for review question: What combined health, social care**
3 **and education service delivery arrangements can best provide for the needs of**
4 **disabled children and young people with severe complex needs on a palliative**
5 **or advance care plan, and for the needs of their families and carers?**

6 No evidence was identified which was applicable to this review question.

7

1 **Appendix I – Economic model**

2 **Economic model for review question: What combined health, social care and**
3 **education service delivery arrangements can best provide for the needs of**
4 **disabled children and young people with severe complex needs on a palliative**
5 **or advance care plan, and for the needs of their families and carers?**

6 No economic analysis was conducted for this review question.

7

1 Appendix J – Excluded studies

2 Excluded studies for review question: What combined health, social care and 3 education service delivery arrangements can best provide for the needs of 4 disabled children and young people with severe complex needs on a palliative 5 or advance care plan, and for the needs of their families and carers?

6 Effectiveness studies

7 **Table 7: Excluded studies and reasons for their exclusion**

Study	Reason for Exclusion
Bennett, R., Proudfoot, J., What does the staff think?: Factors associated with clinical staff perceptions of what constitutes high-quality dying and death at a tertiary pediatric hospital, <i>Journal of Hospice and Palliative Nursing</i> , 18, 470-476, 2016	Population: Staff caring for children within the final 3 days of life. No further information reported about the children. Unclear if they had disabilities and severe complex needs and if they had a palliative/advance care plan
Bona, Kira, Bates, Jennifer, Wolfe, Joanne, Massachusetts' Pediatric Palliative Care Network: Successful Implementation of a Novel State-Funded Pediatric Palliative Care Program, <i>Journal of Palliative Medicine</i> , 14, 1217-1223, 2011	Study design: Non-comparative
Boyden, Jackelyn Y., Curley, Martha A. Q., Deatrick, Janet A., Ersek, Mary, Factors Associated With the Use of U.S. Community-Based Palliative Care for Children With Life-Limiting or Life-Threatening Illnesses and Their Families: An Integrative Review, <i>Journal of pain and symptom management</i> , 55, 117-131, 2018	Study design: Review includes descriptive and qualitative studies only
Byock, I., Twohig, J. S., Merriman, M., Collins, K., Peer-professional workgroups in palliative care: a strategy for advancing professional discourse and practice, <i>Journal of Palliative Medicine</i> , 9, 934-47, 2006	Publication type and outcomes: Overview of workgroup design and outcomes. No quantitative data reported
Byock, Ira, Twohig, Jeanne Sheils, Merriman, Melanie, Collins, Karyn, Promoting excellence in end-of-life care: a report on innovative models of palliative care, <i>Journal of Palliative Medicine</i> , 9, 137-51, 2006	Study design and outcomes: No comparative outcome data reported for the Pediatric Palliative Care Project
Carroll, Jean M., Santucci, Gina, Kang, Tammy I., Feudtner, Chris, Partners in pediatric palliative care: a program to enhance collaboration between hospital and community palliative care services, <i>The American journal of hospice & palliative care</i> , 24, 191-5, 2007	Publication type and outcomes: Overview of collaborative care program. No data on effectiveness
Constantinou, Georgina, Garcia, Rebecca, Cook, Erica, Randhawa, Gurch, Children's unmet palliative care needs: a scoping review of parents' perspectives, <i>BMJ supportive & palliative care</i> , 9, 439-450, 2019	Publication type: Conference poster
Dabbs, Devon, Butterworth, Lori, Hall, Elinor, Tender mercies: increasing access to hospice services for children with life-threatening conditions, <i>MCN. The American journal of</i>	Publication type and study design: Overview of the development of the Children's Hospice and Palliative Care Coalition, including results from a non-comparative survey

Study	Reason for Exclusion
maternal child nursing, 32, 311-9, 2007	
Danvers, L., Freshwater, D., Cheater, F., Wilson, A., Focus. Diana, Princess of Wales Children's Community Team: an evaluation of a multi-professional service for children with life-limiting illnesses, NT Research, 7, 187-199, 2002	Population, publication type and study design: Children with life-limiting illnesses - unclear if they had a palliative or advance care plan. Narrative review and non-comparative study design
Danvers, Lesley, Freshwater, Dawn, Cheater, Francine, Wilson, Andrew, Providing a seamless service for children with life-limiting illness: experiences and recommendations of professional staff at the Diana Princess of Wales Children's Community Service, Journal of clinical nursing, 12, 351-9, 2003	Population and outcomes: Children with life-limiting illnesses - unclear if they had a palliative or advance care plan. Only qualitative outcomes reported
Duncan, Janet, Spengler, Emily, Wolfe, Joanne, Providing pediatric palliative care: PACT in action, MCN. The American journal of maternal child nursing, 32, 279-87, 2007	Outcomes: No relevant outcomes reported
Feudtner, C., Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making, Pediatric Clinics of North America, 54, 583-607, ix, 2007	Publication type: Overview of collaborative communication and paediatric palliative care. No data on effectiveness
Floriani, Ciro A., Home-based palliative care: challenges in the care of technology-dependent children, Jornal de pediatria, 86, 15-20, 2010	Publication type: Narrative review
Friedman, S. L., Helm, D. T., Woodman, A. C., End-of-life care policies and practices in pediatric skilled nursing facilities, American Journal of Hospice & Palliative Medicine, 31, 765-70, 2014	Comparison: No relevant comparative data reported (comparison between different professions and between services with and without official policies)
Friedrichsdorf, Stefan J., Remke, Stacy, Symalla, Barb, Gibbon, Christine, Chrastek, Jody, Developing a pain and palliative care programme at a US children's hospital, International Journal of Palliative Nursing, 13, 534-42, 2007	Publication type: Narrative review and overview of programme development. No data on effectiveness
Great Britain Department of Health, Commissioning children's and young people's palliative care services: a practical guide for primary care trusts and practice-based commissioners, 31p., 2005	Publication type: Commissioning guide. No data on effectiveness
Grunauer, Michelle, Mikesell, Caley, A Review of the Integrated Model of Care: An Opportunity to Respond to Extensive Palliative Care Needs in Pediatric Intensive Care Units in Under-Resourced Settings, Frontiers in Pediatrics, 6, 3, 2018	Publication type: Narrative review
Hancock, L., Lafond, D., Impact of integrating palliative care into a neuro-oncology clinic, Neuro-Oncology, 20, 2018	Publication type: Conference abstract
Harris, Nicola, Beringer, Antonia, Fletcher, Margaret, Families' priorities in life-limiting illness: improving quality with online empowerment, Archives of disease in childhood, 101, 247-52, 2016	Outcomes: No relevant outcomes reported
Hjorth, Elin, Kreicbergs, Ulrika, Sejersen,	Comparison: No relevant comparative data

Study	Reason for Exclusion
Thomas, Jeppesen, Jorgen, Werlauff, Ulla, Rahbek, Jes, Lovgren, Malin, Bereaved Parents More Satisfied With the Care Given to Their Child With Severe Spinal Muscular Atrophy Than Nonbereaved, <i>Journal of child neurology</i> , 34, 104-112, 2019	(comparison between bereaved and non-bereaved parents and different care settings)
Johnson, V., Trowbridge, A., Thorvilson, M., McLay, T., Dombrowski, D., Staying inside the lines while thinking outside the box: Challenges in providing pediatric end-of-life care on general inpatient units at Quaternary Children's Hospitals, <i>Journal of Pain and Symptom Management</i> , 55, 599, 2018	Publication type: Conference abstract
Kiefer, A. C., Kaye, E. C., Blazin, L. J., Baker, J. N., Development of an innovative program to improve provision of palliative and hospice care to children and families in the community: The story of QoLA Kids, <i>Pediatrics</i> , 144, 2019	Publication type: Conference abstract
Kiernan, Gemma, Courtney, Eileen, Ryan, Karen, McQuillan, Regina, Guerin, Suzanne, Parents's experiences of services for their child with a life-limiting neurodevelopmental disability, <i>Children's Health Care</i> , 49, 134-152, 2020	Study design: Mixed methods, including qualitative component and non-comparative survey
Knapp, C., Madden, V., Button, D., Brown, R., Hastie, B., Partnerships between pediatric palliative care and psychiatry, <i>Child & Adolescent Psychiatric Clinics of North America</i> , 19, 423-37, xi, 2010	Publication type: Overview of collaborative paediatric palliative care and psychiatry programmes. No data on effectiveness
Kotwal, N., Kilaikode, S., Koumbourlis, A., Perez, G., Early involvement of palliative care in cystic fibrosis in inpatient setting: A quality improvement initiative, <i>Pediatric Pulmonology</i> , 52, 446, 2017	Publication type: Conference poster
Loeffen, Erik A. H., Tissing, Wim J. E., Schuiling-Otten, Meggi A., de Kruiff, Chris C., Kremer, Leontien C. M., Verhagen, A. A. Eduard, Pediatric Palliative Care-Individualized Care Plan Working, Group, Ball L, Heus G. B. Dabekaussen T. Groot M. Jong M. Kars M. Kasten J. Koot M. Krouwel N. Meij M. Michiels E. Potters M. Meeteren A. S. Spits R. Vallianatos S. Walraven S. V., Individualised advance care planning in children with life-limiting conditions, <i>Archives of disease in childhood</i> , 103, 480-485, 2018	Study design: Non-comparative
Martin, Alice E., Beringer, Antonia J., Advanced care planning 5 years on: An observational study of multi-centred service development for children with life-limiting conditions, <i>Child: Care, Health and Development</i> , 45, 234-240, 2019	Intervention: Staff training intervention carried out between review 1 and review 2. Therefore, comparative data assesses the effectiveness of the educational intervention, not the service model
Maynard, Linda, Lynn, Deborah, Development of a logic model to support a network approach in delivering 24/7 children's palliative care: part one...first of a two-part article, <i>International Journal of Palliative Nursing</i> , 22, 176-184, 2016	Publication type: Overview of development of a 24/7 paediatric palliative care service. No data on effectiveness
Munier, A., When social care and health care	Non-English language

Study	Reason for Exclusion
teams meet the child with special needs, <i>Medicine Palliative</i> , 2018	
Nguyen, L. T., Spear, M. L., Introduction of triggers for palliative care consultation improve utilization and satisfaction within a level 4 NICU, <i>Pediatrics</i> , 142, 2018	Publication type: Conference abstract
Nhs, Confederation, Aiming high for disabled children: delivering improved health services, 18p., 2009	Publication type: Overview of services. No data on effectiveness
Northern Ireland. Department of Health, Social Services, Public, Safety, Service framework for learning disability, 2015	Publication type: Overview of service framework and standards for health and social care. No data on effectiveness
Noyes, Jane, Hastings, Richard P., Lewis, Mary, Hain, Richard, Bennett, Virginia, Hobson, Lucie, Spencer, Llinos Haf, Planning ahead with children with life-limiting conditions and their families: development, implementation and evaluation of 'My Choices', <i>BMC Palliative Care</i> , 12, 5, 2013	Study design: Descriptive survey/qualitative
O'Connor, Margaret, Palfreyman, Stacey, Le, Brian, Lau, Rosalind, Establishing a nurse practitioner model to enhance continuity between palliative care settings, <i>International Journal of Palliative Nursing</i> , 22, 581-585, 2016	Population and study design: Includes CYP and adults and results are not reported separately for CYP. Non-comparative
Ramelet, A. S., Bergstraesser, E., Grandjean, C., Dorsaz, A., Fahrni-Nater, P., Cignacco, E., Zimmerman, K., Comparison of End-of-Life Care Practices between Children with Complex Chronic Conditions and Neonates Dying in an ICU Versus Non-ICUs: A Substudy of the Pediatric End-of-Life Care Needs in Switzerland (PELICAN) Project*, <i>Pediatric Critical Care Medicine</i> , E236-E246, 2020	Comparison: No relevant comparative data (comparison between children and neonates and between ICU and non-ICU settings)
Samsel, C., Ribeiro, M., Ibeziako, P., DeMaso, D. R., Integrated Behavioral Health Care in Pediatric Subspecialty Clinics, <i>Child and Adolescent Psychiatric Clinics of North America</i> , 26, 785-794, 2017	Publication type: Overview of models of care with integrated behavioural health. No data on effectiveness
Scott Ross, Volunteering: vital to our future: how to make the most of volunteering in hospice and palliative care, 76, 2014	Study design and publication type: Narrative review, descriptive survey, examples of good practice, guidance and evaluation toolkit. No data on effectiveness
Sidgwick, P., Randle, E., Petros, A., A three pronged approach to improving advance care planning and end of life decision making for patients with life limiting conditions admitted to picu, <i>Pediatric Critical Care Medicine</i> , 19, 170, 2018	Publication type: Abstract only
Together For Short, Lives, Jointly commissioning palliative care for children and young people aged 0-25 including short breaks: a guide for local areas in England, 23, 2015	Publication type: Commissioning guide
Whitton, C., Williams, C., Wright, B., Jardine, J., Hunt, A., The role of evaluation in the development of a service for children with life-limiting conditions in the community, <i>Child: Care</i> ,	Study design and outcomes: No comparative data for outcomes of interest

Study	Reason for Exclusion
Health & Development, 34, 576-83, 2008	
1 <i>CYP: children and young people; ICU: intensive care unit</i>	

2 Economic studies

- 3 No economic evidence was identified for this review. See Supplement B for further
4 information.
5

1 **Appendix K – Research recommendations – full details**

- 2 **Research recommendations for review question: What combined health, social**
- 3 **care and education service delivery arrangements can best provide for the**
- 4 **needs of disabled children and young people with severe complex needs on a**
- 5 **palliative or advance care plan, and for the needs of their families and carers?**
- 6 No research recommendations were made for this review question.