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1 **What is already known about the topic?**

- 2 • Globally, as demand for palliative care is increasing amongst those with life-limiting illnesses,
3 there has been a rapid growth in specialist and generalist palliative care service provision with a
4 range of different of models of palliative care service provision being developed and
5 implemented internationally.
- 6 • The published evidence has been synthesised in a number of reviews which have attempted to
7 identify the effectiveness and cost effectiveness of different models of palliative care.
- 8 • There is no comprehensive overview of the current evidence base to support decision-making
9 based on the advantages and disadvantages of different models of palliative care or to identify
10 any gaps in the evidence base where more primary research is needed.

11 **What this paper adds?**

- 12 • The outcomes measured vary considerably, making meta-analysis impossible. None-the-less,
13 the available evidence indicates that irrespective of setting or patient characteristics, models of
14 palliative care appear to show benefits for patients and their carers, with no evidence for
15 negative effects. Some models of palliative care may reduce total healthcare costs.
- 16 Heterogeneity, methodological limitations, poor reporting of models and a lack of consensus
17 about outcome measures i.e. what constitutes "benefit to patients" makes it impossible to
18 identify the key components that may enable replication and prediction of which models of
19 provision are most appropriate for specific contexts or for specific patient groups.

20

21

- 1 • In addition to addressing the problems associated with heterogeneity and poor reporting
2 within studies and reviews themselves, this comprehensive and critical review identifies
3 significant gaps in the evidence base and the urgent need to identify models of palliative care
4 by name, define and describe their components in detail in order to differentiate between
5 them in both practice and research. Consensus is required about important outcome
6 measures in palliative care and appropriate, consistent, outcomes should be selected to
7 demonstrate the model's mechanisms of action (i.e. how it works).

8

9 **Implications for practice, theory or policy?**

- 10 • Much has been written and summarised in systematic reviews about models of palliative care
11 in a range of practice settings. However, closer examination of the evidence base highlights a
12 number of areas that warrant further attention for this to be useful to policy makers and
13 clinicians. Much more detailed and systematic reporting of the models in both primary research
14 studies and systematic reviews, ideally using existing checklists such as TIDiER, is essential in
15 order to understand the key components of successful models which could be replicated.
- 16 • Further primary studies are required that assess models of palliative care as complex
17 interventions and enable decision makers to determine which models are likely to be most
18 effective in different settings and for different patient groups.

19 **Abstract**

20 **Background:** A wide range of organisational models of palliative care exist. However, decision makers
21 need more information about which models are likely to be most effective in different settings and for
22 different patient groups.

1 **Aims:** To identify the existing range of models of palliative care that have been evaluated, what is
2 already known and what further information is essential if the most effective and cost-effective models
3 are to be identified and replicated more widely.

4 **Design:** A review of systematic and narrative reviews according to the Preferred Reporting Items for
5 Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Study quality was assessed using the
6 AMSTAR tool.

7 **Data sources:** MEDLINE, EMBASE, PsycINFO, CINAHL, Cochrane Library, Web of Science and ASSIA were
8 searched for reviews about models of service provision from 2000- 2014 and supplemented with Google
9 searches of the grey literature.

10 **Results:** Much of the evidence relates to home based palliative care, although some models are
11 delivered across care settings. Reviews report several potential advantages and few disadvantages of
12 models of palliative care delivery. However, under-reporting of the components of intervention and
13 comparator models are major barriers to the evaluation and implementation of models of palliative
14 care.

15 **Conclusions:** Irrespective of setting or patient characteristics, models of palliative care appear to show
16 benefits and some models of palliative care may reduce total healthcare costs. However, much more
17 detailed and systematic reporting of components and agreement about outcome measures is essential
18 in order to understand the key components and successfully replicate effective organisational models.

19

20 **Keywords:** palliative care, models organizational, systematic review, meta-review

1

2 **Introduction**

3

4 The potential value of palliative care to improve the management of complex care needs and relieve
5 suffering, is increasingly recognised internationally¹. Demographic changes mean populations are living
6 longer with more chronic and complex health needs. Hence, globally, the demand for palliative care is
7 increasing and there has been a rapid growth in palliative care service provision². Models of palliative
8 care service provision are complex interventions³ developing in various ways internationally⁴ to reflect
9 different cultures, religious beliefs, legal frameworks and resource-settings⁵. Centeno et al's (2013) Atlas
10 of Palliative Care⁴ classifies palliative care in Europe based on the place of provision (acute hospital; care
11 in medium and long term places other than general hospitals and at home) and the level of intervention
12 ('basic', 'specialised' or 'other specialised' care). The Atlas⁴ also provides forty-three detailed, country
13 specific reports⁴. Internationally, generalist or specialist models of palliative care are recognised,
14 categorised by the training and experience of the health care practitioners providing care. A key
15 influence on palliative care provision in each country is the way that palliative and health care is
16 funded in different systems. In 2014, the World Health Assembly (WHA) adopted a Resolution⁶
17 calling upon national governments to improve access to palliative care as a core component of
18 health systems.

19 Given the ongoing rapid expansion of palliative care services world-wide and governmental
20 commitments to the WHA (World Health Assembly) Resolution for further expansion, policy makers and
21 service commissioners urgently require evidence to underpin decision-making.

1 *Some work attempting to identify the effectiveness and cost effectiveness of models of palliative care
2 has been completed at review level⁷. However, in addition to evidence about the effectiveness and cost-
3 effectiveness of the various organisational models of palliative care, policy makers need review level
4 evidence about the wider advantages (i.e. benefits to patients, carers, professionals and / or the
5 healthcare system) and disadvantages (i.e. drawbacks to patients, carers and the healthcare system) of
6 different models of palliative care. Furthermore, identifying which components of palliative care models
7 are most appropriate for different patient groups and under what circumstances may provide insight
8 into causal pathways and mechanisms of action (i.e. how each model works). This review of review level
9 evidence builds on the existing body of evidence to assist decision making about services and the future
10 the development and evaluation of these models as complex interventions⁸.Complex interventions are
11 characterised by the number of interacting components they have; the number of groups or
12 organisational levels targeted by the intervention; the number and degree of difficulty of
13 behaviours required by those delivering or receiving the intervention; the number and variability
14 of outcomes and the degree of flexibility or tailoring of the intervention to meet individual needs⁸.
15 As the aim of palliative care is to meet patient's individual and holistic needs, models of care will
16 be developed and tailored to the individual or family's needs in a variety of ways. Hence, a clear
17 statement about the underlying theory of the causal mechanisms (i.e. how the model works, for
18 whom and under what circumstances) would assist the evaluation of models of palliative care.
19 Indeed, understanding the key components of models of palliative care is fundamental to their
20 evaluation. **Research Aim**

21 The overall aim of this systematic review of reviews is to critically evaluate and synthesise the existing
22 evidence base for different types of models of palliative care in different settings and identify the key
23 gaps in the evidence base that still need to be addressed.

1 **Methods**

2 We conducted a systematic review of systematic and narrative reviews of models of palliative care for
3 any adult patient group with life-limiting illnesses. Davidson et al (2006)⁹ describe models of care as an
4 overarching design for health care service provision which consists of defined core elements. We define
5 the term “model” of palliative care service provision as shown in Box 1, providing explicit details about
6 the ‘core elements’ for clarity. Our definition purposefully excludes process models, such as the
7 Liverpool Care Pathway (LCP) or Integrated Care Pathways (ICP), which focus on describing the detailed
8 processes of care provision rather than their structural organisation. The focus on structural models is
9 entirely appropriate given the desire to inform service commissioning.

10

11 Box 1: Definition of “model” of palliative care service provision

12 For this review, the term ‘model’ of palliative care was defined as any structured
13 care model involving multiple components including ‘who *delivers* (e.g.
14 *professionals, paid carers*) the intervention (*specialist or generalist palliative*
care), where (*setting – e.g. hospital*), to whom (*care recipients*), when (*i.e. timing*
and duration), how (*e.g. face to face*) and for what purpose (*i.e. expected*
outcomes)?’”

15 **Search strategy**

16 Our search strategy aimed to identify review-level evidence about different structural models of
17 palliative care. Excluding process models enabled a focus on the resources required to deliver service
18 models rather than processes that assist care delivery.

1 We searched seven databases (MEDLINE via OVID SP, EMBASE via OVID SP, PsycINFO via OVID SP,
2 CINAHL via EBSCO, Cochrane Library via Wiley Interscience (Cochrane Databases of Systematic Reviews
3 and Database of Abstracts of Reviews of Effects) for reviews published in English between 2000 and
4 2014 (Box 2). The search included palliative care terms with a validated systematic review filter¹⁰
5 to maximise sensitivity whilst reducing the number of records retrieved. Searches were conducted in
6 April/May 2014 and updated in October 2014.

7 Reference lists of included reviews were scrutinised to identify additional reviews that potentially met
8 the inclusion criteria. We also undertook Google searches using key search terms ('systematic review',
9 'palliative care,' 'specialist palliative care' and 'adults') to examine ten relevant websites (Marie Curie,
10 Sue Ryder, St Christopher's Hospice, King's Fund, Help the Hospice, The National Institute for Health and
11 Care Excellence (NICE), The World Health Organisation (WHO), The European Association for Palliative
12 Care (EAPC), The National Council for Palliative Care (NCPC) and Hospice UK) for review level evidence
13 on palliative care models.

14

15 ***Study selection***

16 Identified citations were uploaded to a Reference Manager database and duplicate references were
17 removed. Two reviewers independently screened all titles and abstracts (where available) to identify
18 reviews that met the inclusion criteria (Table 1). The full text of potentially relevant titles was
19 independently assessed by two reviewers and, where there was disagreement, a third reviewer was
20 consulted to determine inclusion.

21 ***Assessment of quality of included studies***

1

2 Following study selection, two reviewers independently assessed the methodological quality of included
3 studies using the AMSTAR (A MeaSurement Tool to Assess Reviews) tool¹¹ which was specifically
4 designed to assess the quality of systematic reviews. Scores were totalled, allowing the review to be
5 classified as low quality (3 or lower), medium quality (4 to 7) or high quality (8 to 11). Reviews were
6 included regardless of their quality. (Table 3).

7

8 ***Data extraction***

9 Two reviewers independently extracted data from each included review using predefined and piloted
10 data extraction forms specifically designed for the review. Data were extracted about the key
11 characteristics of the reviews including information about the advantages and disadvantages of models
12 and used to inform Table 2, which was subsequently circulated to all reviewers for confirmation. No
13 additional quality checks were made.

14 ***Synthesis***

15 As the evidence base mainly consists of narrative reviews of studies with diverse methodologies, we
16 undertook a narrative data synthesis following methods outlined by Popay et al (2006)¹². The aim was to
17 undertake a preliminary synthesis, with the intention of explaining which models were effective for
18 which patient groups in which particular settings. We envisaged being able to identify causal pathways
19 and mechanisms of action (i.e. how each model works). We also wanted to explore relationships within
20 and between studies before determining the robustness of the synthesis. The evidence reported in each
21 review was tabulated to provide a descriptive summary of the main characteristics and outcomes of

1 each included review (Table 2). Where reported, we also extracted the definition and a description of
2 the interventions reported as well as their components as described within each review. The lack of
3 detail included in the reviews limited synthesis as it was not possible to identify theory underpinning
4 how and why the intervention works or for whom, although reviews did report on the advantages and
5 disadvantages associated with models.

6 **Results**

7 **Search results**

8 All results are presented in compliance with PRISMA guidelines¹³ (Figure 1). A total of thirteen reviews
9 were identified from the electronic searches. A further four reviews were identified from searching the
10 reference lists of included publications. One further publication⁷, was identified by a scoping exercise
11 which informed the funding bid. This review⁷ is a Health Services Assessment Collaboration publication
12 from New Zealand and was therefore not found within the search strategy. Eighteen reviews^{7,14-30} met
13 the inclusion criteria. AMSTAR quality scores ranged from 2-11 (Table3).

14

15 **Characteristics of included reviews**

16

17 Table 2 summarises the characteristics of included reviews which were published between 2002 and
18 2014, most (n=11) being published in, or after, 2008. Included reviews consisted of studies that involved
19 meta-analyses^{14,15,16,26,28,29}; meta synthesis²⁶ and narrative reviews^{7,17,18,19,20,21,22,23, 24,25,27,30}. One of the
20 narrative reviews present the results by grade of evidence¹³⁷ and another focuses on costs and cost
21 effectiveness data of models across all care settings¹⁸.

1

2 ***Population, intervention, comparator and outcomes reported***

3 Heterogeneity is evident in the adult populations, interventions, comparators and outcomes found in
4 the reviews (Table 2). All reviews consider one or more of the following; health service outcomes,
5 patient outcomes and family or caregiver outcomes. Patient and caregiver outcomes relate to physical
6 (e.g. physical symptoms), psychological (e.g. coping), social issues (e.g. place of care).

7 **The range of models of palliative care**

8 Models are often classified with reference to the setting in which they are delivered. Evidence
9 frequently describes home based palliative care or models that are delivered across care settings (i.e.
10 home, hospital, or inpatient hospice). Using descriptors of the models found in the included reviews for
11 fidelity, these models have been clustered together as follows:

- 12 1. home based palliative care^{14, 15,16} (i.e. models of palliative care delivered within the patient or
13 their carer's own home),
- 14 2. models delivered across multiple settings.

15 Our approach to reporting on the models across settings is pragmatic due to the lack of detailed
16 description of the models in the included publications. The terms used below to 'classify' the models
17 reflect those used in the reviews themselves as it is not possible to develop a typology of models from
18 the scant information available about these in the included reviews. It is not appropriate to re-define
19 these "clusters" as this involves making assumptions about the characteristics of the models identified.
20 Therefore models in this review are 'clustered' according to the terms used to describe the models in
21 the reviews themselves as this best reflects the focus of the included reviews as:

- 1 • palliative care^{7,17,18} or a palliative care approach¹⁹. This includes palliative care for patients with
2 HIV / AIDS¹⁷ and dementia¹⁹ and outpatient palliative care²⁰ for patients with various diagnoses,
3 including cancer, Congestive Heart Failure and Chronic Obstructive Pulmonary Disease
4 delivered in non-hospice settings, including specialist consultations and co-management in
5 clinics, in home or residential home settings.
- 6 • specialised palliative care^{21,22} for patients with various diagnoses or specialist palliative care for
7 patients with cancer²³ including hospice care²⁴ (again, for patients with various diagnoses);
- 8 • a team approach defined as models which provide an integrated team based approach to
9 providing palliative care. Models are described as a palliative care team²⁷ specialist palliative
10 care team²⁶; palliative and hospice care teams (PCHCT)²⁸; an interdisciplinary team approach²⁵;
11 hospital-based palliative care teams²⁹ or dedicated community teams³⁰.

12 Despite limitations in the reporting about models, it is clear that considerable heterogeneity exists in the
13 models of palliative care and their components (Table 2). None-the-less, almost all models appear to
14 involve some specialist palliative care provision (i.e. provision by delivery agents with training in
15 palliative care), albeit that the level of the care providers' training is not explicitly stated in all
16 publications. Often, differences between the models are unclear and models are potentially
17 overlapping. Included reviews report that models are often not well defined or described in original
18 studies, which explains the paucity of subsequent reporting in reviews. A key limitation of the evidence
19 base is the lack of descriptive detail provided about the models which makes it difficult to know how
20 these have been conceptualised and to identify similarities and differences.

21

22 **The advantages and disadvantages of models of palliative care**

1 Insights into causal pathways and mechanisms of action are not evident in the evidence base. Reviews
2 report a range of outcomes conceptualised and measured in different ways. This provides huge
3 challenges in making comparisons across outcomes. The varied reporting of evidence (i.e. by outcome,
4 study, setting or a combination of these) compounds difficulties in comparing review findings. The
5 reporting of the individual models and components is too scant, and too variable for synthesis of
6 findings about which components of palliative care models are most appropriate for different patient
7 groups and under what circumstances across different reviews to be feasible. None-the-less, it is
8 possible to report on the advantages and disadvantages of models as reported in the reviews.

9

10 ***Evidence for home based palliative care models***

11 Three reviews^{14,15,16} report specifically on home based models of palliative care for patients with
12 advanced illness, including malignant and non-malignant conditions (Table 2). Positive benefits of
13 palliative home care services over comparator models (which varied) are reported (see Table 2). The
14 benefits include an increased likelihood of dying at home, as identified in two meta-analyses^{14,16}. A third
15 meta-analysis¹⁵ reports inconclusive, but compelling trends in the evidence in favour of home services
16 increasing home deaths without compromising symptoms, QoL or costs compared to other models that
17 did not include access to home nursing.

18

19

20 ***Evidence for models of care involving provision across different settings:***

1 One review¹⁸ specifically reports on the costs and cost effectiveness of palliative and / or hospice care
2 interventions in any setting (i.e. hospital-based, home-based and hospice care). This review includes
3 home, hospital and hospice based palliative care and therefore appears in more than one section below.
4 The remaining fourteen reviews^{7,17,19,20,21,22,23,24,25,26,27,28,29,30} report on a range of heterogeneous
5 intervention and comparator models of palliative care which have been implemented across a range of
6 contexts and settings.
7 Additionally, the heterogeneity of these models, the limited volume of evidence relating to each service
8 model and the diverse reporting of findings across reviews makes synthesis difficult. Reviews report
9 findings with reference to the outcomes measured^{7,14,15,16,18,22,23,25,30} both interventions and outcomes²⁹
10 or outcomes and themes identified²⁴; method of analysis²⁸, evidence grade¹⁷, setting^{26, 27}, study^{19,20, 21} or
11 study type²⁶.

12

13 ***“Palliative care or a palliative care approach, including outpatient palliative care” :***

14 Four reviews^{7,17,19,20} report some evidence suggesting that palliative care reduces total healthcare costs,
15 with one review suggesting there is reduced healthcare utilization and a lengthening of survival for
16 patients with lung cancer²⁰. Evidence from high quality RCTs indicate a reduction in direct costs for
17 programmes including home care with Palliative Care Team (PCT) support compared to usual care⁷.
18 Home care programmes also reduce the need for acute hospital care⁷. Harding et al (2005)¹⁷ and
19 Sampson et al (2005)¹⁹ provide scant evidence to support their conclusion, possibly due to limitations in
20 the reporting of this data in primary studies. None-the-less, Smith et al’s (2014)¹⁸ more detailed findings
21 which focus on the costs of palliative care concur with these reviews, indicating that, in most cases,
22 palliative care is consistently found to be significantly less costly than comparator models. However,

1 Smith et al (2014)¹⁸ acknowledge that their findings are based on variable cost data that often fails to
2 consider 'out of pocket expenses' or informal care costs. The evidence base for cost-effectiveness is very
3 limited as Smith et al (2014)¹⁸ report on only one cost effectiveness study, the results of which are
4 inconclusive. This finding confirms Arora et al's (2011)⁷ conclusions that the cost-effectiveness of
5 palliative care has not been rigorously assessed.

6 Three reviews^{7,17,20} conclude that there are benefits or trends indicating some benefits of palliative care,
7 including an increase in patient and family / caregiver satisfaction and improvements in symptom
8 control. Rabow et al (2013)²⁰ also report that outpatient palliative care services improve clinician
9 satisfaction. Harding et al's (2005) review¹⁷ reports data that patients with HIV / AIDS receiving home
10 care value the emotional support and high quality of care received, as well as being able to remain at
11 home and avoid hospital visits which was less disruptive of their daily routine. This review¹⁷ also
12 suggests that both home and inpatient hospice care significantly improved anxiety, insight and spiritual
13 wellbeing. Only Arora et al (2011)⁷ reports on place of death, finding inconclusive results in terms of
14 whether patients died at home or not. This review⁷ also reports little evidence of benefits for patient
15 survival, quality of life, patient satisfaction and resource use. A fourth¹⁹ review concludes that there is
16 insufficient evidence to indicate benefits of a palliative care approach for patients with dementia. None
17 of these four reviews^{7,17,19,20} found evidence to suggest that palliative care worsens patient or caregiver
18 outcomes.

19 ***Specialised or specialist Palliative Care including models of hospice care:***

20 Four reviews^{21,22,23,24} report on specialised or specialist palliative care, including models of hospice care.

1 Three of these reviews report on the costs of specialist or specialised palliative care^{21,22,24}. Although
2 limited cost data exist, reviews concur that the models are associated with cost savings, usually due to a
3 reduction in general health care use²⁴, emergency care use²⁴, hospital costs (although this review also
4 reports that home and hospice care costs increased when patients were referred to a palliative care
5 programme)²² and inpatient stays²¹. Smith et al (2014)¹⁸ report that cost savings associated with
6 palliative care are largely due to significant differences in hospital readmission rates compared to
7 patients receiving 'usual care'. However, it is not clear whether the cost savings are attributable to
8 specialist palliative care in Smith et al's (2014)¹⁸ review.

9

10 Although Candy et al (2011)²⁴ found that hospice care delivered at home increases death not occurring
11 in hospital, effective pain relief and patient and family satisfaction with care, reviews of other
12 specialised palliative care services do not concur with these findings. Garcia-Perez et al (2009)²¹ found
13 that all reviews conclude that no specific model of specialised palliative care is more effective or cost
14 effective than others with regard to symptom control, QoL, emotional support and satisfaction.
15 Zimmermann et al (2008)²² concur with Garcia-Perez et al's (2009)²¹ findings for symptom control, QoL
16 and patient satisfaction, but report consistent improvements in family satisfaction with specialised
17 palliative care. Candy et al (2011)²⁴ concur reporting an increase in patient and family satisfaction when
18 hospice care is provided in a variety of settings including hospital, nursing home or a patient's home.
19 Qualitative findings in their review²⁴ also suggest that hospice care is highly valued by patients and
20 families, whilst hospice day care generates a renewed sense of meaning and purpose for patients. Home
21 hospice services support families to sustain patient care at home.

1 Davies and Higginson, (2005)²³ also identify some advantages of specialist palliative care day services in
2 terms of high patient satisfaction and the value of social contact with staff and other patients.

3

4

5 ***Palliative Care Teams:***

6

7 Six reviews report on palliative care teams^{25,26,27,28,29,30}. Although one meta synthesis reports wide
8 variations in the type of service delivered by such teams, there is no discernible difference in outcomes
9 between service delivery in cities, urban, and rural areas and evidence of benefit is strongest for home
10 care²⁴. Multidisciplinary teams are found to be more effective than unidisciplinary teams in one
11 review²⁷.

12

13 Although five reviews^{26,27,28,29,30} all identify some advantages of team based models of palliative care in
14 terms of effectiveness, one review based on four studies of varying quality reports little evidence to
15 support the effectiveness of interdisciplinary teams²⁵. In terms of specific outcomes, a team approach is
16 found to improve pain and symptom control^{26,27,28,29,30} and reduce anxiety in some cases²⁶. Additionally,
17 although some reviews report mixed findings about satisfaction^{29,30}, most report that palliative care
18 teams increase patient^{25,27} and especially carer satisfaction^{27,28,30}, with one not specifying whether
19 satisfaction increases for patients, carers or both groups²⁶.

20

1 Reviews suggest that the impact of palliative care teams on home deaths was equivocal²⁸ but hospice at
2 home teams lead to more home deaths and fewer deaths in nursing homes³⁰. Although one review
3 indicates no differences in hospital use, others suggest that specialist palliative care teams have
4 advantages in terms of reducing hospital admissions and length of hospital stays^{26,27}. One review
5 reports that home hospice reduces costs²⁷. Cost savings are attributed to transfer of costs from hospital
6 to home in one review²⁹ and differences in length of stay in another review²⁸. Smith et al (2014)¹⁸
7 support the latter finding reporting that the average length of stay was significantly shorter for palliative
8 care patients compared to the control group.

9

10 **Evidence for the effectiveness, cost-effectiveness and appropriateness of the different models of**
11 **palliative care for different patient groups in different contexts**

12 Heterogeneity and methodological limitations make it impossible to identify the relative advantages and
13 disadvantages of different models for different patient groups or in different contexts. However, all
14 reviews highlight a number of potential advantages and relatively few disadvantages for all models of
15 palliative care. Although all reviews identify the delivery agent(s) and care recipients, few details are
16 given about delivery mechanisms or the context and settings, timing, duration and circumstances in
17 which models are delivered. Comparator models are often described as 'usual care' but many reviews
18 provide no further detail about the components of these models, meaning that it is not possible to
19 determine which components of the models may influence outcomes.

20

21 **Discussion**

1 The publications included in this systematic review of review level evidence report a range of
2 heterogeneous models of palliative care in terms of their definitions, descriptions, components and
3 outcome measures. Most reviews relate to specialist palliative care services, defined as those delivered
4 by staff working primarily in palliative care and with training in this speciality. Irrespective of setting or
5 patient group, models of palliative care included in the reviews appear to show potential benefits for
6 patients and their carers, with no evidence of negative effects. There is some evidence to suggest that
7 some models may result in reduced total healthcare costs.

8 The heterogeneous nature of the interventions across the various care settings means that there is little
9 evidence at review level relating to relevant settings such as nursing homes³¹. No reviews examining
10 palliative care for people with mental health issues or learning disabilities, who have specific needs and
11 preferences^{35,36} were identified.

12 'Usual,' 'standard' or 'conventional' care is often a comparator model but not well defined or described
13 and likely to vary considerably between countries given international differences in conceptualisations
14 of palliative care³². The lack of detailed descriptions of both interventions and comparators at review
15 level may result from reporting restrictions (e.g. word limitations). However, the limited description of
16 models makes it difficult to discern differences between models of palliative care and draw firm
17 conclusions from our review, especially as we cannot be certain that there are no overlaps in the way
18 models have been 'clustered' in this review. Consequently, it was also difficult to draw conclusions
19 about the efficacy of the individual components of any model. In common with other reviews of review
20 level evidence that focus on models of palliative care^{7,33} heterogeneity in the study designs, populations,
21 interventions and outcomes of the included reviews precluded meta-analysis and meta synthesis.

22

1 Hoffman et al (2014)³⁴ offer suggestions about how better reporting of interventions can be achieved
2 using the 12 item template for intervention description and replication (TIDieR) checklist and guide, an
3 extension of the CONSORT 2010 statement (item 5)³¹ and the SPIRIT 2013 statement (item 11)³⁶.
4 Developed for the reporting of all types of evaluative studies, the TIDieR checklist³⁴ could also be used
5 when reporting on interventions in systematic and narrative reviews. Although the TIDieR checklist³⁴
6 prompt authors to describe interventions in enough detail to enable replication, the guidelines highlight
7 issues that caused difficulty within this review. For example, in addition to the limited reporting about
8 their components, models are not easy to find or recognise as few are known by specific names or
9 described in a manner that allows identification. The lack of detail about the aim, rationale and the
10 components of models reported in reviews perhaps reflects the lack of attention that has been given to
11 the theoretical underpinning of these complex interventions³. The lack of conceptual underpinning for
12 models may also explain the recognised variation in the outcomes measured³⁷. Some work to explain
13 the mechanisms of action and causal pathways of the models developed and evaluated is fundamental
14 to successfully determining what is likely to be effective⁸. Indeed, the complex nature of palliative care
15 and the difficulties in identifying which components, if any, are important and has been recognised by
16 McQuay (2011)³⁸.

17

18 Outcome reporting is also a key issue to address in palliative care practice and research^{37,39} especially in
19 the evaluation of complex interventions⁴⁰ such as models of care where there is a need to explain
20 mechanisms of action⁴¹ and identify how these relate to intermediate and final outcomes⁴⁰. Diverse
21 outcomes are assessed for patients, family members and caregivers, staff members and professionals in
22 palliative and hospice care using a wide range of assessment instruments in published studies³⁷.

1 Agreement about important outcomes and consistency in outcome measures is essential if national and
2 international comparisons are to be made in the evaluation of palliative care services³⁹. However,
3 irrespective of the well documented methodological challenges of outcome measurement in palliative
4 care³⁷, consensus will not be easy to establish, especially as the outcomes of interest are likely to vary
5 among stakeholders and levels (i.e. individual, family, community, societal). The EAPC (2015)³⁹
6 recognise outcome measurement as key to understanding different models of care and recommend the
7 introduction of outcomes that allow for national and international comparisons.

8

9 **Comparison with findings of previous reviews of palliative care models:**

10

11 The findings of our review are consistent with those reported in other reviews of review level
12 evidence^{7,33,42,43}, despite differences in the scope and methods used. Both Lockett et al (2014)³³ and
13 Arora et al (2011)⁷ completed both a review of reviews and a review of primary studies undertaken by a
14 single researcher respectively. Our review included any type of review and any outcome, whereas Arora
15 et al (2011)⁷ limited the review to eight commonly reported outcomes. The limitation of Arora et al's
16 (2011)⁷ inclusion criteria seems apparent given that Stiel et al's (2012)³⁷ systematic review reported the
17 existence of over 500 instruments to measure outcomes. However, our findings indicate that the
18 outcomes selected by Arora et al (2011)⁷ are those most frequently reported. In keeping with our
19 findings, Keirse et al (2009)⁴³ found that most evidence relates to home models of palliative care (taking
20 into account that home models are included in some models provided across settings), and conclude
21 that heterogeneity in terms of the aims, caregivers, target populations and interventions make it

1 difficult to compare models with regard to cost-effectiveness . In keeping with others^{7,33}, we found poor
2 quality information and a general lack of reporting about the components of the various types of
3 models. The difficulties associated with synthesising data about disparate models of palliative care has
4 also been previously acknowledged^{20,22}.

5

6 **Quality of included reviews and primary studies:**

7 The generally weak quality of evidence of the primary studies on which the included reviews were based
8 is largely due to the well documented methodological challenges faced by researchers within the field of
9 palliative care^{3,44,45}. These methodological difficulties consequently impact on the quality and
10 usefulness of reviews in palliative care⁴⁶. None-the-less, Wee et al (2008)⁴⁶ acknowledge that reviews
11 can inform the palliative care community about the limited evidence base and indicate deficiencies in
12 the primary evidence base. The lack of controlled trials in palliative care makes use of findings from
13 well-designed nonrandomized controlled trials inevitable.⁴⁷

14 **Strengths and limitations of this review of reviews**

15 Restriction to English language searches introduces a potential bias⁴⁸, as does the mainly UK focus of the
16 grey literature searches. The broad aims and the inclusion of all outcomes in an attempt to provide
17 a comprehensive review of reviews may have generated additional challenges in terms of data
18 analysis and reporting. However, despite ensuring that the Amstar criteria⁷ for a high quality review
19 are met, this review is also weakened by the poor reporting of heterogeneous models of palliative care
20 and the lack of standardised outcome measures, a known problem in the field of palliative care³⁷.

1 Poor reporting makes the development of a typology of models impossible. Although ‘clustering’ models
2 provides some consistency of reporting between included reviews and our own, models are potentially
3 overlapping as similarities and differences between models are not clear. Consequently, we cannot be
4 sure of the effect that these clusters may have on the reporting of relevant outcomes. Irrespective
5 of the clustering, it is evident that all reviews highlight some advantages of models and very few
6 limitations.

7 The differences in palliative care provision between countries and contexts means that models vary
8 considerably, making comparisons difficult. The wider generalisability of the review to low or middle
9 income countries is limited, since the evidence originates from largely high income countries where
10 populations are rapidly ageing and more is spent on health care⁴⁶. A mapping review shows a paucity of
11 research in international palliative care, and particularly highlights a lack of research from low to middle
12 income regions⁴⁹. This lack of evidence, combined with complexities in transferring evidence from
13 different contexts, means that cross-country comparisons are likely to remain challenging.

14 **Implications for policy and practice**

15 This review of reviews shows a substantial body of evidence which, overall, supports the development
16 and implementation of a range of different models for providing palliative care, across different settings
17 and for different clinical conditions and patient groups. However, it remains difficult to conclude which
18 models may be the most effective, cost-effective and appropriate to different contexts and therefore
19 such decisions will still be largely based on the preferences of local providers and commissioners and the
20 availability of the required staff, resources and facilities.

21 **Implications for research**

1 Better reporting of interventions and comparators in primary research is likely to subsequently increase
2 the value of systematic reviews in terms of providing the best evidence⁵⁰, improving the standard of
3 evaluative research³ (especially as Randomised Controlled Trials (RCTs) are often inadequate in palliative
4 care⁵¹), better understanding complexity⁸, mechanisms of action and critical components of models of
5 care.

6 **Conclusions**

7 A range of models of palliative care are reported in mainly medium to high quality published review
8 evidence, most of which are narrative reviews based on non-randomised studies. Most available
9 evidence relates to home care. Reviews highlight a number of potential advantages and few
10 disadvantages of models of palliative care. However, the heterogeneous nature and the poor quality of
11 reporting about the components of the models makes it difficult to draw any conclusions about which
12 models are most appropriate in different contexts or for different patient groups. The under-reporting
13 of the components of intervention and comparator model is a major barrier to the evaluation and
14 implementation of models of palliative care.

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19 *Conflict of interest statement:*

20 The authors declare that there is no conflict of interest.

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4 Further information / supplementary material can be found at:

5 <http://www.integrate-hta.eu>

6 *DISCLAIMER: The sole responsibility for the content of this manuscript lies with the authors. It does not*
7 *necessarily reflect the opinion of the European Union. The European Commission is not responsible for*
8 *any use that may be made of the information contained therein.*

9

1

2 **Box 2 Search Terms**

3

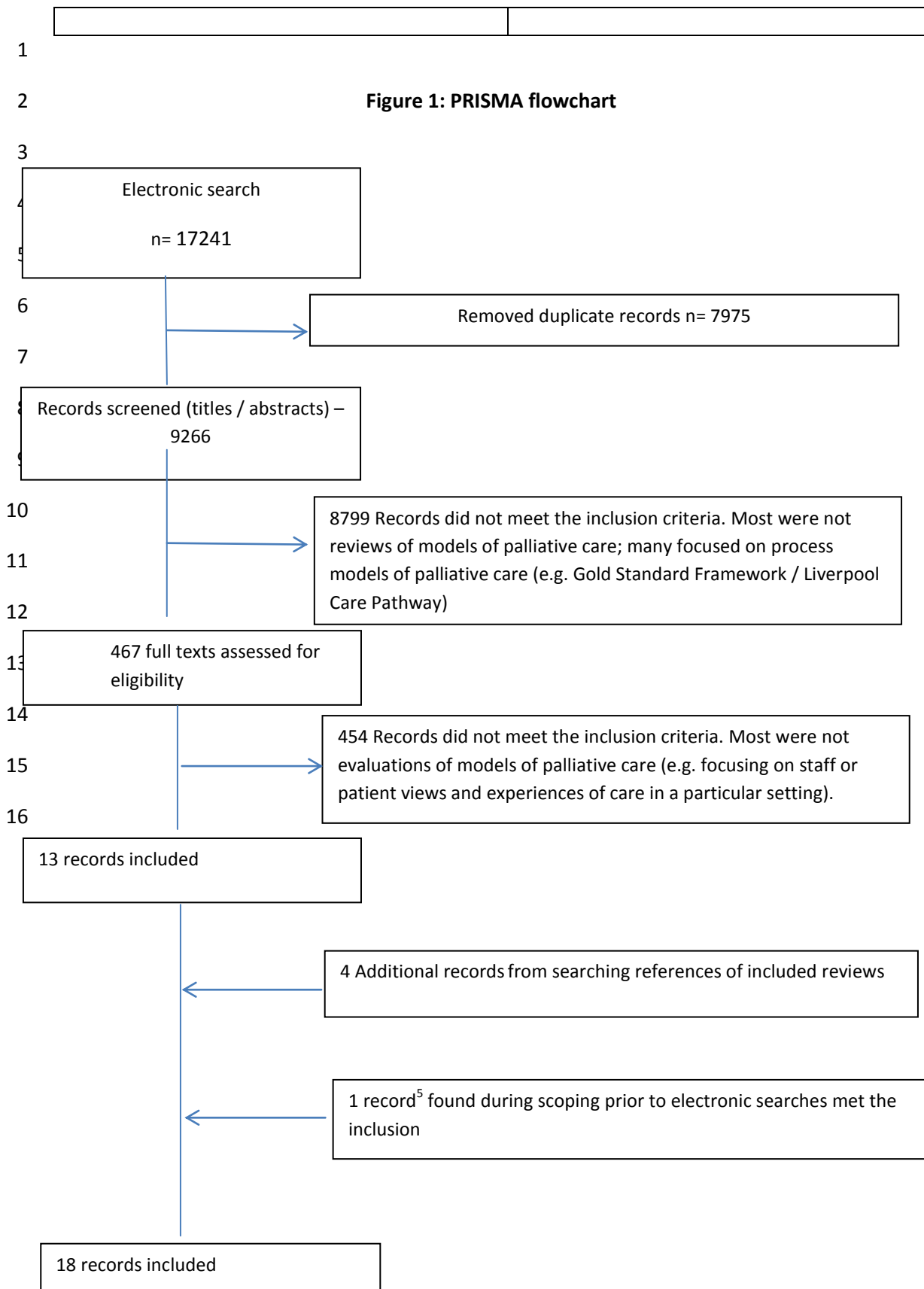
Search Terms	
1	Advance care planning/
2	Attitude to death/
3	Bereavement/
4	Death/
5	Hospices/
6	Hospice Care/
7	Palliative care/
8	Right to die/
9	Terminal care/
10	Terminally ill/
11	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12	(Attitude\$ adj2 (death\$ or dying or care or caring)).ti,ab.
13	Bereave*.ti,ab.
14	(EOL or end of life).ti,ab.
15	Hospice*.ti,ab.
16	(Imm* adj2 death).ti,ab.
17	(Incurabl* adj2 ill*).ti,ab.
18	(Limit* adj2 life).ti,ab.
19	Palliat*.ti,ab.)
20	((Respite or support*) adj2 (care or caring)).ti,ab.
21	(Terminal and (care or caring or ill* or disease*)).ti,ab.
22	12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
23	11 or 22
24	MEDLINE.tw.
25	Systematic review.tw.
26	Meta-analysis.pt.
27	Intervention\$.ti.
28	24 or 25 or 26 or 27
29	23 and 28
30	Limit 29 to (English language and humans and yr="2000 - 2014")

4

1

2 **Table 1: Inclusion criteria:**

Inclusion	Exclusion
<p>Study type: Review level evidence reporting models of palliative care. Publications reporting systematic reviews of all types of original study (intervention, observational and qualitative studies). Reviews of reviews will be included when the findings related to the primary studies can be considered independently of the review of review findings in the publication.</p>	<p>Publications that are not review level evidence (i.e. primary studies). Publications or reviews that are not systematic in evidence search, retrieval appraisal, synthesis and analysis Opinion papers, editorials and conference abstracts.</p>
<p>Dates: Systematic & narrative reviews published between 2000- 2014.</p>	<p>Dates: Systematic & narrative reviews published outside of the date range 2000-2014.</p>
<p>Population: Reviews considering adults (defined as people aged 18 and over) with life-limiting illnesses as defined by the study authors. Reviews considering populations of varying ages will be included providing the focus of the research is adults, not children or adolescents.</p>	<p>Reviews solely considering children and adolescents (defined as those aged under 18 years of age)..</p>
<p>Intervention: Reviews considering models of palliative care for any palliative care patient group.</p>	<p>Reviews will be excluded if focus is <u>not</u> a model of palliative care or is a single intervention used in palliative care. Models of palliative care provided at specific phases of the disease trajectory (e.g. bereavement services only).</p>
<p>Comparator: Any model of palliative care (specialist or generalist) provided at any point in the disease trajectory (i.e. from diagnosis to death) OR any form of 'usual' or 'routine' care. There may be no comparator.</p>	<p>We did not exclude reviews based on the comparator</p>
<p>Outcomes: All outcomes that are reported will be examined.</p>	<p>We did not exclude Reviews based on outcomes reported.</p>
<p>Language: written in English.</p>	<p>Language: Reviews not written in English,</p>



Review of models of palliative care

Table 2: Characteristics of included reviews:

Author, year, country or origin type of review & AMSTAR score	Review question/aim	Type and number of studies included	Population	Intervention	Comparator model(s) Or none	Primary Outcome	Key conclusions
HOME SETTING							
Gomes et al 2013¹⁴ UK Cochrane systematic review & meta analysis where appropriate. AMSTAR score - 11	To evaluate the impact of home palliative care services on outcomes for adults with advanced illness or their family caregivers or both.	Included controlled intervention studies. Identified 23 studies in 84 records	Adults with terminal illness, their family carers or both in receipt of home palliative care services	Home palliative care and 'reinforced' home palliative care (i.e. with an additional component of carer support)	Usual care' defined in various ways (comparator for Home palliative care) Care from specialist palliative care teams (comparator for 'reinforced' home palliative care).	Death at home	Home palliative care more than doubles the odds of dying at home
Lockett et al 2013¹⁵ Australia Systematic review & meta analysis AMSTAR score - 9	To compare the effect of Specialist Palliative care Services (SPCSs) providing home nursing vs. other models of service delivery on rates of home deaths.	Included comparative studies of any design that used quantitative evaluation. Identified 9 studies in 10 records.	Patients with life limiting illnesses; receiving nursing care exclusively at home.	Interventions delivering nursing care exclusively in the home rather than only through a day hospital or inpatient services.	an alternative that did not include access to home nursing.	Rates of home deaths	Inconclusive evidence that community SPCSs offering home nursing increase home deaths without compromising symptoms, QoL or increasing costs

Review of models of palliative care

<p>Shepperd et al 2011¹⁶ UK</p> <p>Cochrane systematic review & Meta analysis / narrative summary where meta-analysis not possible</p> <p>AMSTAR score - 11</p>	<p>To determine if home-based end of life care reduces the likelihood of dying in hospital and what effect this has on patients' symptoms, quality of life, health service costs and care giver's satisfaction compared with inpatient hospital or hospice care.</p>	<p>Included controlled intervention studies. Identified 4 trials.</p>	<p>Adults aged 18 with various diagnoses and over who require terminal care at the end of life.</p>	<p>End of life care at home</p>	<p>Inpatient hospital or hospice care</p>	<p>Place of death Patients' preferred place of death</p>	<p>Patients receiving home-based end of life care were more likely to die a home compared with those receiving usual care (p=0.0002).</p>
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ACROSS SETTINGS: PALLIATIVE CARE OR A PALLIATIVE CARE APPROACH							
<p>Arora et al 2011⁷ New Zealand</p> <p>Part 2 – Narrative review of original studies</p> <p>AMSTAR score - 7</p>	<p>To compare the efficacy of different models of palliative care</p>	<p>Included adequately powered comparative studies. Identified 27 eligible studies in 34 records.</p>	<p>Adult palliative care patients as defined by the NZ Palliative Care Strategy (2001). Most had advanced cancer. Some study populations focused on family members / carers.</p>	<p>Any international structures, programs, systems or models of palliative care from different settings.</p>	<p>Any alternative structure, program, system or model of palliative care (including no structured program).</p>	<p>A range of outcomes including:</p> <ol style="list-style-type: none"> 1. Patient quality of life 2. Patient satisfaction 3. Symptom control 4. Caregiver satisfaction 5. Place of death 6. Survival 7. Utilisation of resources 8. Cost of care 	<p>Heterogeneous models of palliative care with inconsistent results were found. Little evidence of benefits in favour of the intervention for home deaths, patient survival, quality of life, patient satisfaction and resource use. Home-care programmes reduced the need for acute hospital care. Some high-quality RCTs reported reduced costs for home care programs with PCT support.</p>

Review of models of palliative care

<p>Harding et al 2005¹⁷ UK</p> <p>Narrative review presented by evidence grade</p> <p>AMSTAR score - 6</p>	<p>To appraise the effect of models of palliative care on patient outcomes.</p>	<p>Included original research of any design. Identified 22 services that had in 17 records.</p>	<p>Population infected with any stage of HIV / AIDS (or HIV infected subsample analysed and reported separately).</p>	<p>Home based care; home palliative care/hospice at home; hospice inpatient; hospital inpatient palliative care; specialist AIDS inpatient unit; and hospital inpatient and outpatient care.</p>	<p>Not stated</p>	<p>Various outcomes measured including pain and symptom control, patient and family anxiety, patient and family insight, communication and spiritual well-being.. Satisfaction with care, medical procedures and investigations, perceived quality of care, patient involvement, support, and quality of life.</p>	<p>Both home palliative care and inpatient hospice care significantly improved pain and symptom control, anxiety, insight, and spiritual wellbeing.</p>
<p>Sampson et al. 2005¹⁹ UK</p> <p>Narrative review presented by study</p> <p>AMSTAR score - 5</p>	<p>A systematic review assessing the efficacy of a palliative care model in patients with dementia.</p>	<p>Included any evaluative study design. Identified 2 studies- A randomized control trial & a prospective cohort study</p>	<p>Adults with a diagnosis of dementia.</p>	<p>Palliative care - Dementia Special Care Unit and an unidentified intervention in the 2nd study.</p>	<p>Dementia Special Care Unit compared to traditional long-term care comparator not stated in the 2nd study</p>	<p>Patient discomfort, medical resource utilization and mortality rates.</p>	<p>Equivocal (uncertain) evidence of the efficacy for a palliative model of care in dementia.</p>

Review of models of palliative care

<p>Rabow et al 2013²⁰</p> <p>UK</p> <p>Narrative review presented by study</p> <p>AMSTAR score - 5</p>	<p>To assess the evidence of the impact of non-hospice outpatient palliative care services (defined as including specialty consultations and co-management in clinics, homes, or residential living facilities)</p>	<p>Included prospective, randomised controlled trials. Identified 4 studies.</p>	<p>Patients with late stage COPD, CHF and cancer; advanced cancer and metastatic non-small cell lung cancer and their family caregivers.</p>	<p>Outpatient palliative care services for terminally ill patients (i.e. in outpatient clinics, primary care clinics; in home or via telephone).</p>	<p>Usual care which included usual primary care and usual oncology care. Usual care was not described.</p>	<p>Impact of outpatient palliative care on patient, family caregiver, and clinician satisfaction; clinical outcomes including symptom management, quality of life, and mortality; and health care utilization outcomes.</p>	<p>Outpatient palliative care services can: improve patient satisfaction, symptom control and quality of life. These services also reduce health care utilization& costs and lengthens survival in lung cancer patients. Family and clinician satisfaction improved.</p>
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ACROSS SETTINGS: SPECIALIST PALLIATIVE CARE & HOSPICE							
<p>Garcia-Perez et al. 2009²¹ Spain.</p> <p>Narrative review presented by study.</p> <p>AMSTAR score - 6</p>	<p>To assess & synthesise evidence on the effectiveness and cost effectiveness of specialised palliative care for terminally ill patients, comparing different organisational models with one another.</p>	<p>Included comparative study designs examining two or more specialised palliative care programmes in adults with terminal illness. Identified 2 studies.</p>	<p>Adults (18 years and older) with terminal illness included in a palliative care programme.</p>	<p>Specialised palliative care programmes (i.e. Full palliative care team; Telephone palliative care team; In patient and home hospices and specialist palliative care unit).</p>	<p>Comparing different organisational models of specialised palliative care provision with each other.</p>	<p>Pain and other symptom control, psychological symptoms, health-related quality of life, well-being, functional state, satisfaction, place of death, number of patients cared, number of home visits, number of days at hospital.</p>	<p>None of the programmes studied are more effective (in terms of symptom control, QoL, emotional support or satisfaction) or cost-effective than another.</p>

Review of models of palliative care

<p>Zimmermann et al. 2009²². Canada</p> <p>Qualitative narrative synthesis.</p> <p>AMSTAR score - 8</p>	<p>To systematically examine the evidence for the effectiveness of specialized palliative care in improving quality of life, satisfaction with care, and economic cost.</p>	<p>Included randomised controlled trials. Identified 22 records.</p>	<p>Population with mixed diagnoses including cancer, COPD, Congestive Heart Failure (CHF) Motor Neurone Disease & AIDS</p>	<p>A specialized palliative care service was defined as a service of professionals that provides or coordinates comprehensive care for patients with a terminal illness.</p>	<p>'Usual care' in a variety of settings. 'Standard' hospital, hospice or home care. Mailed self help materials. Office care; Telephone consultation or 4 week waiting list.</p>	<p>Patient or caregiver quality of life, satisfaction with care, or economic cost. (Quality-of-life measures were not specific for terminally ill patients.)</p>	<p>Little evidence for benefit with regard to quality of life, symptom control and patient satisfaction or cost. However, specialized palliative care (SPC) consistently improves family satisfaction with care.</p>
<p>Davies & Higginson 2005²³. UK</p> <p>Systematic review quantitative and qualitative analysis.</p> <p>AMSTAR score - 4</p>	<p>To systematically review the evidence for how the structure and process of palliative day care relate to outcomes for adults with cancer.</p>	<p>Included qualitative and quantitative studies examining the outcomes of interest. Identified 12 records.</p>	<p>Adults with cancer.</p>	<p>Specialist palliative day-care</p>	<p>Where stated, 'usual palliative care (not defined)</p>	<p>Symptom control, quality of life, social and psychological support, and patient and relative satisfaction with care</p>	<p>Patient satisfaction is high among those attending day-care. No model of care was found to be better than any other in terms of outcomes. Patients seem to value the social contact with staff and other patients that day care visits provide.</p>

Review of models of palliative care

<p>Candy et al 2011²⁴ UK</p> <p>Systematic review quantitative and qualitative analysis</p> <p>AMSTAR score - 8</p>	<p>To identify evidence for the effectiveness, including cost-effectiveness, of hospices, and hospice care in a patient's home and in nursing homes and for the experiences of those who use and of those who provide such services.</p>	<p>Included quantitative comparative study designs for evaluation of effectiveness and qualitative thematic evaluations to identify patient, family and service providers' experience of hospice type services. Identified 22 records.</p>	<p>Patients with a variety of cancer and non-cancer diagnoses in the final phases of terminal disease and family caregivers or family members.</p>	<p>Hospice (defined as holistic provision to patient and family by MDT at a dedicated hospice facility) at home, in a nursing home or other care facility in the community</p>	<p>Usual generalist care for comparative studies</p>	<p>Symptom management, pain assessment and other aspects of patient care, satisfaction with services, family carer well-being such as care burden and bereavement /grief, health service use, costs, and place of death, patients' emotional well-being</p>	<p>Quantitative evidence shows that hospice care reduces general health service use and costs, and increases effective pain relief, death not occurring in hospital and patient and family satisfaction with care</p> <p>Qualitative findings suggest that hospice care is highly valued by patients and families. Home hospice services support families to sustain patient care at home. Hospice day care services generate a renewed sense of meaning and purpose for patients.</p>
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ACROSS SETTINGS: TEAM APPROACH							
<p>Leclerc et al 2014²⁵ Canada</p> <p>Narrative review</p> <p>AMSTAR score - 9</p>	<p>To determine the effectiveness, harms and adverse effects of the interdisciplinary team approach to providing end of life palliative care to adult patients and their home caregivers compared to other approaches.</p>	<p>Included comparative studies of any quantitative or qualitative design. Identified 4 studies in 5 records.</p>	<p>In-patients or community dwelling patients aged 18 or over with stage III or IV cancer or a terminal condition with a prognosis of a year or less to live who received care in any setting.</p>	<p>'Interdisciplinary' teams or interventions</p>	<p>A group that did not receive care from an interdisciplinary team.</p>	<p>Outcomes relate to patients, patients' family members, home caregivers, healthcare providers or the healthcare system as well as adverse effects related to y aspect..</p>	<p>Interdisciplinary palliative care teams can improve patients' satisfaction with palliative care, hospital care and health providers' communication Patients were satisfied with the chances of dying at home and were less likely to visit the emergency department or be hospitalised.</p>

Review of models of palliative care

<p>Higginson & Evans 2010²⁶ UK</p> <p>Systematic review & Meta synthesis</p> <p>AMSTAR score - 8</p>	<p>To determine whether specialist palliative care teams (SPCTs) improve outcomes for patients with advanced cancer and their caregivers, in terms of improving symptoms and quality of life and/or reducing the emotional concerns of family caregivers.</p>	<p>Included controlled and observational studies evaluating palliative care. Identified 39 studies in 40 records.</p>	<p>Patients with advanced cancer & family carers</p>	<p>Specialist palliative care in a community, hospital (inpatient/outpatient), and /or hospice setting.</p>	<p>Usual care (present or historical). Usual care comprised conventional community and general hospital/oncology services.</p>	<p>Pain and symptom management, quality of life and death. Patient and carer satisfaction/morbidity before and after bereavement.</p>	<p>SPCTs show benefit for patients with cancer in hospital, home or inpatient services. Significant benefits exist in terms of improving pain and symptom control, satisfaction, anxiety and health care outcomes (i.e. reduced hospital admissions and length of stays). Some studies indicated lower costs.</p>
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Review of models of palliative care

<p>Finlay et al 2002²⁷</p> <p>UK</p> <p>Systematic review quantitative and qualitative analysis</p> <p>AMSTAR score – 2</p>	<p>To assess whether there was an effect of palliative care teams.</p>	<p>Included grade I – III evidence (qualitative and quantitative reports). Identified 43 studies.</p>	<p>Not clearly stated, although adults mentioned in included tables.</p>	<p>Palliative care teams / subgroups of teams in hospital, home and hospice (not defined).</p>	<p>Usual generalist care for comparative studies. Conventional care.</p>	<p>15 outcomes in 5 areas: 1) Patient group 2) Carer (pre-bereavement) group - 3) Carer (post-bereavement.) - 4) Patient/carers group - 5) Professionals group -</p>	<p>Small positive benefits for hospice and palliative care teams exist. Palliative care teams seem effective in differing settings. Multidisciplinary teams have advantages over uni-disciplinary teams(e.g. reduce length of hospital stay) Improved pain and symptom control, satisfaction for carers and patients.Home care reduced costs. In patient hospice resulted in greater satisfaction (especially for carers). In patient hospice and palliative care services either improved symptom control or had no effect and findings were equivocal regarding QoL.</p>
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Review of models of palliative care

<p>Higginson et al 2003²⁸</p> <p>UK</p> <p>Meta-analysis, meta-synthesis and meta-regression</p> <p>AMSTAR score – 10</p>	<p>To determine the effectiveness of palliative and hospice care teams (PCHCT),</p>	<p>Included evaluative controlled, comparative and observational studies. Identified 44 studies in 69 records.</p>	<p>Patients with a progressive life threatening illness and their caregivers (defined as family, friends, or significant others).</p>	<p>Palliative and hospice care teams (PCHCT) defined as two or more health care workers, at least one of whom had specialist training or worked mainly in palliative or hospice care. PCHCT were home care, hospital-based combined home/hospital care, inpatient units, and integrated teams.</p>	<p>Usual care was routine community and general hospital/oncology services.</p>	<p>Range of patient and caregiver outcomes:</p>	<p>A meta-regression of 26 studies indicated a slight positive effect on patient outcomes, but no effect on caregiver outcomes. Meta-analysis of 19 RCTs or quasi-experimental studies demonstrated small but significant benefit on patients' pain other symptoms and a non-significant trend towards benefits for satisfaction.</p>
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Review of models of palliative care

<p>Higginson Finlay et al 2002²⁹ Do hospital based teams UK</p> <p>meta-analysis, meta-synthesis</p> <p>AMSTAR score - 11</p>	<p>To determine whether hospital-based palliative care teams improve the process or outcomes of care for patients and families at the end of life.</p>	<p>Included evaluative – trial design comparing hospital-based palliative care with usual care delivery (present or historical). Identified 13 studies.</p>	<p>Patients with a progressive life-threatening illness, and their family, carers, or close friends.</p>	<p>Palliative Care Teams working in hospitals (defined as two or more health care workers at least one of whom had specialist training or worked mainly in palliative care). Interventions were very varied.</p>	<p>Usual care (either current or historical)</p>	<p>A broad range of outcomes and process measures related to: Patients, Carer/family member pre/post-bereavement, Population, Professionals</p>	<p>Hospital-based palliative care teams offer some benefits e.g reduced time in hospital and improved symptom management. Satisfaction and quality of life improved in some studies. Some benefits exist for carers and the service.</p>
<p>Thomas et al, 2006³⁰</p> <p>Canada</p> <p>Dedicated community teams Narrative review</p> <p>AMSTAR score – 6</p>	<p>To identify and analyse all published RCTs that focus on the organization of EOL care provided to persons who are terminally ill, near death, or dying.</p>	<p>Included 23 RCTs of palliative care – 12 of which focused on examined the effect of Providing Palliative Care through Dedicated Community Teams.</p>	<p>Terminally ill people near death, or dying, including patients with advanced cancer. Close family members were included in 1 study</p>	<p>Dedicated Community Teams (described in various ways)</p>	<p>Routine or standard care usual EOL care ; customary Veterans Affairs post discharge Care; conventional care; standard home care or to office care</p>	<p>a. ratings of QoL and symptom management b. satisfaction with care c. the duration of the palliative period and the place of death d. costs of palliative care compared to usual care</p>	<p>Community or home-based EOL care associated with improved QoL and symptom management. There were mixed findings about patient/carer satisfaction Cost data were inconclusive</p>

ACROSS ALL SETTINGS – COSTS AND COST EFFECTIVENESS							
<p>Smith et al 2014¹⁸ Ireland</p> <p>Narrative review of cost and cost effectiveness</p> <p>AMSTAR score - 7</p>	<p>Identify studies that investigate the cost or resource use implications or cost-effectiveness of a 'palliative care intervention' relative to some type of comparator or control.</p>	<p>Included any comparative study design examining the cost and/or utilisation implications of a palliative care intervention. Identified 46 eligible studies.</p>	<p>Limited information was provided about study population. Where stated, cancer & non cancer Patients with advanced illness</p>	<p>A range of hospital-based, home-based and hospice care) models of palliative care</p>	<p>A range of models described in various ways as usual care; conventional care or non-PC hospital-based care.</p>	<p>Costs or resource use implications and cost-effectiveness (n=1): point estimates that indicate that the intervention is cost-saving</p>	<p>Palliative care is most often less costly than comparators Palliative care has a mixed impact on resource utilisation</p>

Table 3: Quality appraisal* of included reviews

*Adapted from the AMSTAR tool

Criteria	7	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
1. Was an a priori design provided?	CA	Y	Y	Y	Y	CA	CA	Y	Y	Y	Y	CA	CA	Y	CA	Y	Y	CA
2. Was there duplicate study selection and data extraction?	N	Y	N	Y	Y	CA	Y	CA	Y	Y	CA	Y	y	CA	CA	Y	Y	Y
3. Was a comprehensive literature search performed?	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	y	Y	CA	Y	Y	y
4. Was the status of publication (i.e. grey literature) used as an inclusion criteria?	N	N	Y	N	CA	Y	N	N	CA	Y	Y	CA	N	CA	CA	N	N	Y

Review of models of palliative care

5. Was a list of studies (included and excluded) provided?	N	Y	Y	Y	N	Y	Y	N	N	N	N	Y	Y	Y	N	Y	Y	Y
6. Were the characteristics of the included studies provided?	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
7. Was the scientific quality of the included studies assessed and documented?	Y	Y	Y	Y	Y	Y	N	N	Y	Y	N	Y	Y	Y	N	Y	Y	Y
8. Was the scientific quality of the included studies used appropriately in formulating conclusions?	Y	Y	Y	Y	Y	Y	N	N	N	Y	N	Y	Y	Y	Y	Y	Y	N
9. Were the methods used to combine the findings of the studies appropriate?	Y	Y	Y	Y	N/A	Y	N	Y	Y	Y	Y	Y	Y	Y	CA	Y	Y	Y
10. Was the likelihood of publication bias assessed?	Y	Y	Y	Y	N	N	N	N	N	N	N	N	Y	Y	N	Y	Y	N
11. Was the conflict of interest	N	Y	Y	Y	N	Y	Y	Y	Y	Y	N	Y	N	N	N	N	Y	N

Review of models of palliative care

stated?																		
AMSTAR scores:	7	11	9	11	6	7	5	5	6	8	4	8	9	8	2	10	11	6
<p>Y = Yes, N= No, CA = Can't Answer , N/A= Not applicable</p> <p>Quality Scores Yes scores 1 point, except for question 4 where No scores 1 point .</p> <p>Quality is described as: High – 8-11; Medium – 4-7; Low - 3 or lower</p>																		

References

1. Kirk, T. W. (2011). The meaning, limitations and possibilities of making palliative care a public health priority by declaring it a human right. *Public Health Ethics*, 4(1), 84-92.
2. Centeno, C et al., (2013) "EAPC Atlas of Palliative Care in Europe 2013 - Full Edition" Milano: EAPC (European Association for Palliative Care), <http://hdl.handle.net/10171/29291>.
3. Higginson, I. J., Evans, C. J., Grande, G., Preston, N., Morgan, M., McCrone, P., ... & Murray, S. A. (2013). Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC medicine*, 11(1), 1.
4. Centeno C, Clark D, Lynch T, et al. Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC Task Force. *Palliat Med* 2007; 21: 463–471.
5. Higginson, I.J., Gomes, B., Calanzani, N., Gao, W., Bausewein, C., Daveson, B.A., Deliens, L., Ferreira, P.L., Toscani, F., Gysels, M. and Ceulemans, L. (2014). Priorities for treatment, care and information if faced with serious illness: A comparative population-based survey in seven European countries. *Palliative medicine*, 28(2), 101-110.
6. World Health Assembly (2014) Item 15.5: Strengthening of palliative care as a component of comprehensive care throughout the life course. Minutes of the SIXTY-SEVENTH WORLD HEALTH ASSEMBLY http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf (accessed 16 January 2017)
7. Arora, N., Standfield, L. and Weston (2011) A. Systematic review of systems of palliative

Care *HSAC Report*; 4 (22).

8. Craig P, Dieppe P, Macintyre S et al (2008) Developing and evaluating complex interventions: New guidance 2008. Medical Research Council [on-line]. Available at

<http://www.mrc.ac.uk/complexinterventionsguidance>.

9. Davidson P, Halcomb E, Hickman L, Phillips J, Graham B (2006) Beyond the rhetoric: what do we mean by a 'model of care'? *Australian Journal Advanced Nursing* 23(3):47-55

10. Lee, E., Dobbins, M., DeCorby, K., McRae, L., Tirilis, D., & Husson, H. (2012). An optimal search filter for retrieving systematic reviews and meta-analyses. *BMC medical research methodology*, 12(1), 51.

11. Shea, B.J., Hamel, C., Wells, G.A., Bouter, L.M., Kristjansson, E., Grimshaw, J., Henry, D.A. and Boers, M. (2009). AMSTAR is a reliable and valid measurement tool to assess the methodological quality of systematic reviews. *Journal of clinical epidemiology*, 62(10), 1013-1020.

12. Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M. and Britten, N. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme. Version 1. Lancaster: Institute of Health Research*.

13. Moher D, Liberati A, Tetzlaff J, Altman D, and the Prisma Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA guidelines. *BMJ*, 2009; 339: 332-336.

14 Gomes, B., Calanzani, N., Curiale, V., McCrone, P., & Higginson, I. J. (2013). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev*, 6(6).

- 15 Lockett, T., Davidson, P. M., Lam, L., Phillips, J., Currow, D. C., & Agar, M. (2013). Do community specialist palliative care services that provide home nursing increase rates of home death for people with life-limiting illnesses? A systematic review and meta-analysis of comparative studies. *Journal of pain and symptom management*, *45*(2), 279-297.
- 16 Shepperd, S., Wee, B., & Straus, S. E. (2011). Hospital at home: home-based end of life care. *Cochrane Database of Systematic Reviews*, *7*.
17. Harding, R., Karus, D., Easterbrook, P., Raveis, V. H., Higginson, I. J., & Marconi, K. (2005). Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. *Sexually Transmitted Infections*, *81*(1), 5-14.
18. Smith, S., Brick, A., O'Hara, S., & Normand, C. (2014). Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative medicine*, *28*(2), 130-150
19. Sampson, E. L., Ritchie, C. W., Lai, R., Raven, P. W., & Blanchard, M. R. (2005). A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogeriatrics*, *17*(01), 31-40.
20. Rabow, M., Kvale, E., Barbour, L., Cassel, J. B., Cohen, S., Jackson, V., ... & Weissman, D. (2013). Moving upstream: a review of the evidence of the impact of outpatient palliative care. *Journal of palliative medicine*, *16*(12), 1540-1549.
21. García-Pérez, L., Linertová, R., Martín-Olivera, R., Serrano-Aguilar, P., & Benítez-Rosario, M. A. (2008). A systematic review of specialised palliative care for terminal patients: which model is better?. *Palliative medicine*.

22. Zimmermann, C., Riechelmann, R., Krzyzanowska, M., Rodin, G., & Tannock, I. (2008). Effectiveness of specialized palliative care: a systematic review. *Jama*, 299(14), 1698-1709.
23. Davies, E., & Higginson, I. J. (2005). Systematic review of specialist palliative day-care for adults with cancer. *Supportive care in cancer*, 13(8), 607-627.
24. Candy, B., Holman, A., Leurent, B., Davis, S., & Jones, L. (2011). Hospice care delivered at home, in nursing homes and in dedicated hospice facilities: A systematic review of quantitative and qualitative evidence. *International journal of nursing studies*, 48(1), 121-133.
25. Leclerc, B. S., Blanchard, L., Cantinotti, M., Couturier, Y., Gervais, D., Lessard, S., & Mongeau, S. (2014). The effectiveness of interdisciplinary teams in end-of-life palliative care: a systematic review of comparative studies. *Journal of palliative care*, 30(1), 44-54.
26. Higginson, I. J., & Evans, C. J. (2010). What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *The Cancer Journal*, 16(5), 423-435.
27. Finlay, I. G., Higginson, I. J., Goodwin, D. M., Cook, A. M., Edwards, A. G. K., Hood, K., ... & Normand, C. E. (2002). Palliative care in hospital, hospice, at home: results from a systematic review. *Annals of Oncology*, 13(suppl 4), 257-264
28. Higginson, I. J., Finlay, I. G., Goodwin, D. M., Hood, K., Edwards, A. G., Cook, A., ... & Normand, C. E. (2003). Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers?. *Journal of pain and symptom management*, 25(2), 150-168.
29. Higginson, I. J., Finlay, I., Goodwin, D. M., Cook, A. M., Hood, K., Edwards, A. G., ... & Norman, C. E. (2002). Do hospital-based palliative teams improve care for patients or families at the end of life?. *Journal of pain and symptom management*, 23(2), 96-106.

- 30 Thomas RE, Wilson D, and Sheps S. (2006) A literature review of randomised controlled trials of the organisation of care at the end of life. *Canadian Journal on Aging* 25:271-293.
31. Seymour, J. E., Kumar, A., & Froggatt, K. (2011). Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. *Palliative Medicine*, 0269216310387964.
32. Radbruch, L., & Payne, S. (2009). White paper on standards and norms for hospice and palliative care in Europe: part 1. *European journal of palliative care*, 16(6), 278-289.
33. Lockett, T., Phillips, J., Agar, M., Virdun, C., Green, A., & Davidson, P. M. (2014). Elements of effective palliative care models: a rapid review. *BMC health services research*, 14(1), 136.
34. Hoffmann, T. C., Glasziou, P. P., Boutron, I., Milne, R., Perera, R., Moher, D., ... & Lamb, S. E. (2014). Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *Bmj*, 348, g1687.
35. Schulz K, Altman D, Moher D, CONSORT Group. CONSORT 2010 Statement: updated guidelines for reporting parallel group randomised trials. *BMJ* 2010;340:c332.
36. Chan A, Tetzlaff J, Gøtzsche P, Altman D, Mann H, Berlin J, et al. SPIRIT 2013 explanation and elaboration: guidance for protocols of clinical trials. *BMJ* 2013;346:e7586.
- 33.
37. Stiel, S., Pastrana, T., Balzer, C., Elsner, F., Ostgathe, C., & Radbruch, L. (2012). Outcome assessment instruments in palliative and hospice care—a review of the literature. *Supportive care in cancer*, 20(11), 2879-2.

38. McQuay, H. (2011). Evidence-based medicine: What is the evidence that it has made a difference?. *Palliative medicine*, 25(5), 394-397.

39. Bausewein, Claudia, Barbara A. Daveson, David C. Currow, Julia Downing, Luc Deliens, Lukas Radbruch, Kath Defilippi et al. "EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services—Recommendations from the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement." *Palliative medicine* (2015): 0269216315589898

40. Petticrew, M., Anderson, L., Elder, R., Grimshaw, J., Hopkins, D., Hahn, R., Krause, L., Kristjansson, E., Mercer, S., Sipe, T. and Tugwell, P., 2013. Complex interventions and their implications for systematic reviews: a pragmatic approach. *Journal of clinical epidemiology*, 66(11), pp.1209-1214.

41. Anderson, L.M., Oliver, S.R., Michie, S., Rehfuss, E., Noyes, J. and Shemilt, I., 2013. Investigating complexity in systematic reviews of interventions by using a spectrum of methods. *Journal of clinical epidemiology*, 66(11), pp.1223-1229.

42. Francke, A. L. (2000). Evaluative research on palliative support teams: a literature review. *Patient education and counseling*, 41(1), 83-91.

43. Keirse E, Beguin C, Desmedt M, Deveugle M, Menten J, Simoens S, Wens J, Borgermans L, Kohn L, Spinnewijn B, Cardinael A, Kутten B, Vandenberghe P, and Paulus D. (2009) Organisation of palliative care in Belgium - supplement. Health Services Research. Available from: https://kce.fgov.be/sites/default/files/page_documents/d20091027342.pdf (2009 accessed 22 March 2016).

44. McMillan, S. C., & Weitzner, M. A. (2003, January). Methodologic issues in collecting data from debilitated patients with cancer near the end of life. In *Oncology nursing forum* (Vol. 30, No. 1).

45. Higginson, I. J., McCrone, P., Hart, S. R., Burman, R., Silber, E., & Edmonds, P. M. (2009). Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. *Journal of pain and symptom management*, 38(6), 816-826.

46. Wee, B., Hadley, G., & Derry, S. (2008). How useful are systematic reviews for informing palliative care practice? Survey of 25 Cochrane systematic reviews. *BMC palliative care*, 7(1), 13.

47. Kongsgaard, U. E., & Werner, M. U. (2009). Evidence-based medicine works best when there is evidence: challenges in palliative medicine when randomized controlled trials are not possible. *Journal of pain & palliative care pharmacotherapy*, 23(1), 48-50.

48. Egger, M., Juni, P., Bartlett, C., Holenstein, F., and Sterne, J. (2003). How important are comprehensive literature searches and the assessment of trial quality in systematic reviews?: Health Technology Assessment 7 (1).

49. Clark J, Gardiner C, Barnes A. International palliative care research in the context of global development: a systematic mapping review. *BMJ Supportive & Palliative Care* (in press).

.

50. Evans, D. (2003) Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. *Journal of clinical nursing*, 12(1), 77-84.

51. Aoun, S. M., & Kristjanson, L. J. (2005). Challenging the framework for evidence in palliative care research. *Palliative Medicine*, 19(6), 461-465.

