

[Josie Dixon](#), [Tihana Matosevic](#) and [Martin Knapp](#)

The economic evidence for advance care planning: systematic review of evidence

**Article (Accepted version)
(Refereed)**

Original citation:

Dixon, Josie, Matosevic, Tihana and Knapp, Martin (2015) *The economic evidence for advance care planning: systematic review of evidence*. [Palliative Medicine](#). pp. 1-28. ISSN 0269-2163 (In Press)

© 2015 The Authors

This version available at: <http://eprints.lse.ac.uk/61793/>

Available in LSE Research Online: May 2015

LSE has developed LSE Research Online so that users may access research output of the School. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LSE Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain. You may freely distribute the URL (<http://eprints.lse.ac.uk>) of the LSE Research Online website.

This document is the author's final accepted version of the journal article. There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

The Economic Evidence for Advance Care Planning: Systematic Review of Evidence

Dixon, Josie*, Matosevic, Tihana* and Knapp, Martin*

*Personal Social Services Research Unit (PSSRU), London School of Economics and Political Science (LSE)

CORRESPONDING AUTHOR

Josie Dixon

PSSRU

London School of Economics and Political Science

Houghton Street

London WC2A 2AE

Tel: 07989 070 777

Email: j.e.dixon@lse.ac.uk

This paper presents independent research funded by the National Institute for Health Research School for Social Care Research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR SSCR, NHS, the National Institute for Health Research or the Department of Health.

ABSTRACT

Background: Advance care planning (ACP), a process of discussion and review concerning future care in the event of losing capacity. Aimed at improving the appropriateness and quality of care, it is also often considered a means of controlling health spending at the end of life.

Aim: To review and summarise economic evidence on advance care planning.

Design: A systematic review of academic literature.

Data sources: We searched for English language peer-reviewed journal articles, 1990 to 2014, using relevant research databases; PubMed; ProQuest; CINAHL Plus with Full Text; EconLit; PsycINFO; SocINDEX with Full Text and International Bibliography of the Social Sciences. Empirical studies using statistical methods in which ACP and costs are analytic variables were included.

Results: There are no published cost-effectiveness studies. Included studies focus on health care savings, usually associated with reduced hospital care. ACP may be associated with healthcare savings for some people, in some circumstances, such as people living with dementia in the community, in nursing homes or in areas with high end of life care spending.

Conclusions: There is need for clearer articulation of the likely mechanisms by which ACP can lead to reduced care costs or improved cost-effectiveness, particularly for people who retain capacity. There is a need to consider wider costs, including intervention costs and the costs of substitute health, social and informal care. There is no evidence that ACP is more expensive. Economic outcomes should be considered in the context of quality benefits.

What is already known about the topic?

- In the US there is legislation to promote advance care planning, while advance care planning is a key feature of UK policy on end of life care
- Aimed at improving the appropriateness and quality of care, advance care planning is also often considered to be a means of making better use of healthcare resources at the end of life

- Whether advance care planning can lead to cost savings or cost-effectiveness gains is the subject of ongoing debate

What this paper adds?

- This paper provides an overview of empirical studies, published since 1990, reporting on economic outcomes associated with advance care planning
- Research evidence is limited and heterogeneous but suggests that advance care planning may lead to health care savings for some people in some circumstances
- Cost measures are varied, with no studies taking a societal perspective and many relevant costs omitted

Implications for practice: theory or policy?

- Advance care planning may lead to cost savings in some circumstances and is unlikely to be more expensive
- There is a need for clearer articulation of the likely mechanisms by which advance care plans can lead to reduced care costs or cost-effectiveness gains
- Economic outcomes should be considered in the wider context of quality benefits

1. Background

Advance care planning (ACP) is a voluntary process of discussion and review concerning future care and treatment in the event of losing capacity. ACP conversations need not be documented although usually they are. The legal and policy framework for advance care planning varies across countries. In the UK, advance statements set out general preferences to inform best-interest decisions, while advance decisions to refuse treatment are legally binding and regulated by the Mental Capacity Act (2005) in England and Wales and, with similar provision, by common law in Scotland and Northern Ireland. Advance decisions may also include assigning proxy decision-making powers through power of attorney, Lasting Power of Attorney (LPA) in England and Wales and Power of Attorney (PoA) in Scotland. In Northern Ireland there is no legal provision for health and welfare proxy decision-making. ACP is an im-

portant element in UK policy on end of life care, featuring in national end of life strategies for England and Wales (Department of Health, 2008), Scotland (Scottish Government, 2008) and Northern Ireland (Department of Health, Social Services and Public Health, 2010). In the US, advance decisions are known as advance directives (ADs) and the Patient Self-Determination Act (PSDA, 1990) places an obligation on healthcare facilities to inform patients about their rights to make an advance healthcare directive. Advance directives may also include assigning Durable Power of Attorney (DPoA).

Potential benefits of ACP include care aligned with preferences, reduced misunderstandings and conflict between medical staff and families, fewer interventions of limited clinical value, earlier access to palliative care, reduced emergency hospital admissions, fewer hospital deaths and reduced anxiety and depression experienced by bereaved carers (Brinkman-Stoppelenburg et al., 2014; GMC, 2010). Although primarily concerned with improving the appropriateness and quality of care, ACP is also often considered a means of controlling health spending and making better use of resources at the end of life (Marckmann and In Der Schmitten, 2013). Whether ACP can lead to cost savings or cost-effectiveness gains in practice has been an ongoing source of debate.

2. Aims

Our aim was to systematically review the academic literature for empirical studies that report on economic outcomes potentially associated with ACP, published between 1990 and 2014. We included studies in which ACP forms an important and substantial element of a wider palliative care or support programme. In this paper, we present and critically discuss the evidence, and make proposals for future research in this area.

3. Methods

A systematic search of academic literature was conducted with support from a research librarian, following national guidance on the conduct of systematic reviews in healthcare (Centre for Review and Dissemination, 2008). We searched for English language peer-reviewed journal articles, 1990 to 2014, using relevant research databases (PubMed; ProQuest; CINAHL Plus with Full text; EconLit; PsycINFO; SocINDEX with Full Text and International Bibliography of the Social Sciences), using relevant search terms (Box 1).

Box 1: Search terms

“advance care plan” or “advanced care plan” or “advance care plans” or “advanced care plans” or “advance care planning” or “advanced care planning” or “advance statement” or “advanced statement” or “advance statements” or “advanced statements” or “advance directive” or “advanced directive” or “advance directives” or “advanced directives” or “advance decision” or “advanced decision” or “advance decisions” or “advanced decisions” or “living will” or "end of life planning" or "end-of-life planning" or "EOL planning" or "end of life conversation" or "end-of-life conversation" or "EOL conversation" or "end of life discussion" or "end-of-life discussion" or "EOL discussion" or "end of life care planning" or "end-of-life care planning" or "EOL care planning" or "end of life counselling" or "end-of-life counselling" or "EOL counselling" or "end of life counseling" or "end-of-life counseling" or "EOL counseling"

AND

“cost” or “costs” or “spend” or “spending” or “expenditure” or “savings”

For each of the selected databases, we searched for ACP terms in the title, abstract and keywords. We considered that if one of the selected terms for ACP did not occur in the abstract, title or keywords, then the study was unlikely to include ACP as a key variable in empirical research. Conservatively, however, we allowed for the cost-related terms to appear anywhere, including in the full text (with the exception of

PubMed, where the search facility allowed only titles and abstracts to be searched). The initial search generated a total of 474 journal articles (following removal of 89 duplicates). In addition, we separately searched, using the cost-related terms, all PubMed articles categorised using the Mesh term, 'Advance Care Planning'. This MESH term was introduced in 2003. It draws together published articles on ACP and is defined as 'discussions with patients and/or their representatives about the goals and desired direction of the patient's care, particularly end of life care, in the event that the patient is or becomes incompetent to make decisions'. This produced 108 additional articles (after removing 131 duplicates with the original list). In total, across all searches, we identified 582 unique articles. The lead author, assisted by another researcher, reviewed titles and abstracts and articles that turned out to be unrelated to ACP for end of life (n=102) were removed, leaving 480 articles in total.

Abstracts and, where necessary, full papers for the 480 articles were reviewed against inclusion and exclusion criteria. Inclusion criteria were:

- an empirical study using statistical methods
- ACP included as an analytical variable, defined as including ADs or advance decisions; advance care statements or written plans; and/or ACP discussions
- a comparison between people engaging and not engaging in ACP
- costs, expenditure or savings included as an analytical variable.

Articles were excluded which did not meet the above criteria. Other exclusion criteria were:

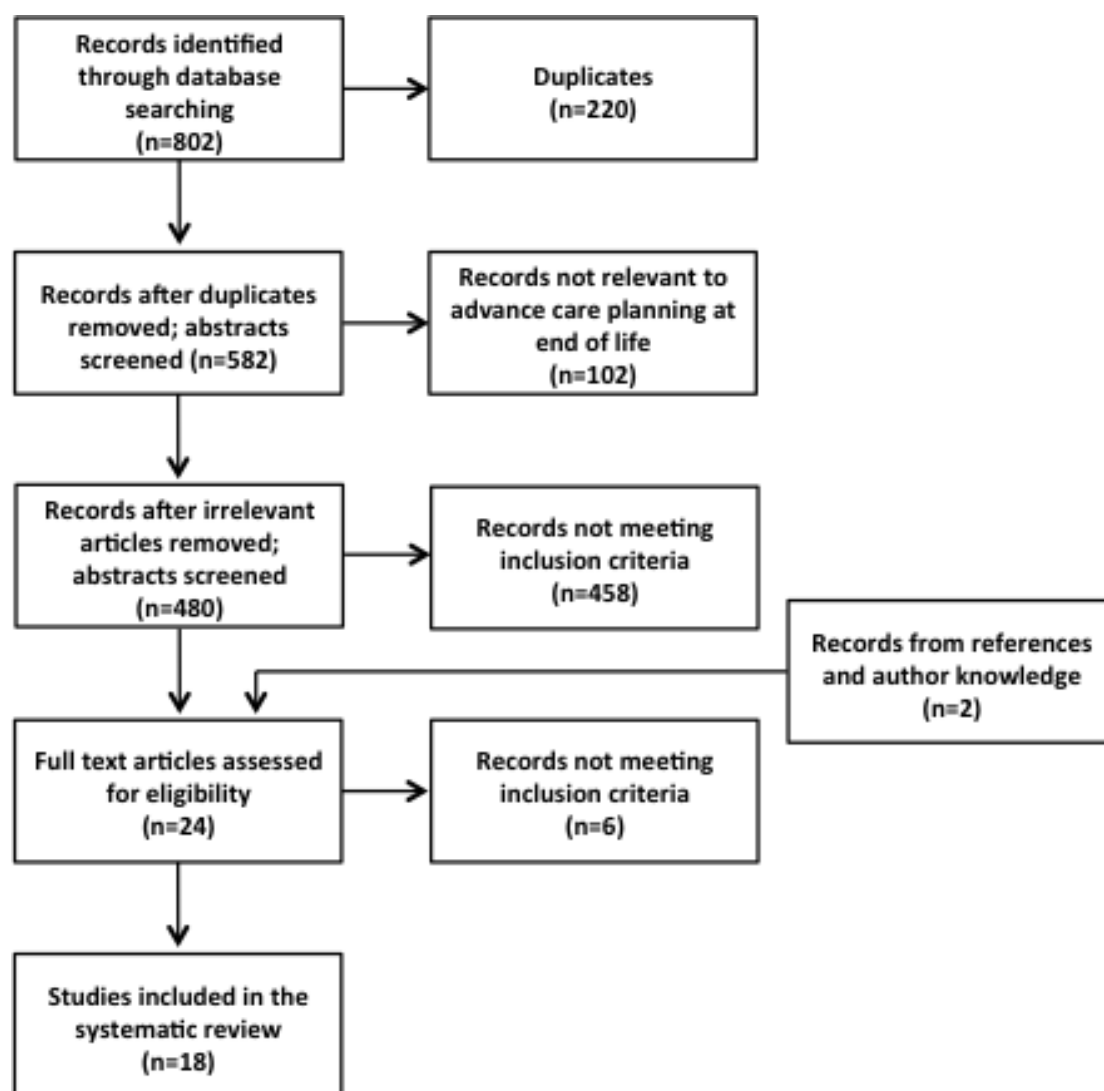
- studies of psychiatric patients
- studies of children (aged under 18)
- studies solely about medical orders (e.g. do-not-hospitalise; do-not-resuscitate)
- studies solely about LPA or DPOA

We included studies that considered ACP as part of a wider palliative care or end of life intervention as long as ACP formed an important and substantial element. Although we were aware that this meant that the impact of ACP could not be isolated from the rest of the intervention, we included such studies to provide a comprehensive

overview of ACP-related studies reporting economic outcomes. DPOA and specific medical orders (e.g. do-not-resuscitate or do-not-hospitalize orders) were not searched for separately, as we were interested in these only where they were part of a broader written advance care plan or ACP process. The reasons for this were that DPOA does not always involve discussion or documentation of a patient's wishes, while medical orders are often applied late, often just days before death, and not always with full discussion with either the patient or their carers or family members (Brinkman-Stoppelenburg et al., 2014). Two articles that were found solely to cover DPOA or specific medical orders were excluded (Maksoud et al., 1993; Fonk et al., 2012). In one case a study that otherwise met the criteria for inclusion was removed since, although ACP formed an important part of the intervention (in three UK nursing homes), in practice, only 40 out of the total of 165 patients received any ACP facilitation and support (although other aspects of the programme were implemented fully) (Lisk et al., 2012).

Where systematic and narrative reviews were identified in the search, they were reviewed with the aim of identifying further empirical studies not identified in the original search. Reference lists in included articles were also hand-searched for additional studies of relevance. One study was identified by these means (Gade et al., 2008). A further study, from the UK, independently known to the authors, was also included (Baker et al. 2012). This appeared in the *British Journal of General Practice*, which was not included in the selected databases. In total 24 full papers were reviewed. The final number of included studies was 18.

Figure 1: Flowchart showing selection process



Following selection, descriptive data about the 18 included studies was extracted, covering year of publication, country, type of ACP activity or intervention, target population and setting, sample and sample size, study design, economic outcome measures used and results. The level of evidence was graded according to the schema used by Brinkman-Stoppelenburg et al. (2014) in their systematic review of (non-economic) outcomes associated with ACP, which were adapted from criteria originally proposed by Higginson et al. (2002) (Box 2). The results from this data extraction are presented in Table 1.

BOX 2: Definitions used for the grades of evidence (Reproduced from Brinkman-Stoppelenburg, 2014, based on criteria originally identified by Higginson et al., 2002)

Grade I: Randomised controlled trial (RCT) or RCT review

- IA Calculation of sample size* and accurate, standard definition of outcome variables
- IB Accurate and standard definition of outcome variables.
- IC Neither of the above

Grade II: Prospective study with a comparison group (non-randomised controlled trial, good observational study) or retrospective study which controls effectively for confounding variables

- IIA Calculation of sample size* and accurate, standard definition of outcome variables and adjustments for the effects of important confounding variables
- IIB One or more of the above
- IIC Neither of the above

Grade III: Retrospective or observational or cross-sectional studies

- IIIA Comparison group, calculation of sample size* and accurate, standard definition of outcome variables
- IIIB One or more of the above
- IIIC Neither of the above

* If the number of respondents was 1000 or more, we considered the criterion of ‘calculation of sample size’ to be met.

Further data, focusing on key features of definition and design, were extracted to inform our discussion. Throughout we use US terminology (e.g. AD), reflecting the predominance of US-based research literature in this area, but when not used in reference to a specific study or otherwise stated, we intend this to include the parallel terms. When discussing US studies, the term hospice refers to palliative care provided in any setting where life expectancy is less than 6 months. When discussing UK studies, hospice refers to a UK hospice organisation, providing palliative care to people with a terminal diagnosis.

4. Results

Table 1 summarizes the results from the review.

[insert table 1 here]

Country

Research in this area predominantly comes from the US, following the Patient Self-Determination Act (1990). All but four of the 18 included studies are from the US, with two from the UK (Abel et al., 2013; Baker et al., 2012), one from Canada (Molloy et al., 2000) and one from Singapore (Teo et al., 2014).

Study design

Five of the studies use randomised designs; four randomised controlled trials (RCTs) (Hamlet et al., 2010; Engelhardt et al., 2006; Teno et al., 1997; Gade et al., 2008) and one cluster-randomised controlled trial (Molloy et al., 2000). These evaluate different types of ACP intervention in a variety of settings, including nursing homes (Molloy et al., 2000), hospitals (Gade et al., 2008; Teno et al., 1997), a home-based telephone counselling intervention (Hamlet et al., 2010) and a complex care and coordination programme delivered through Veteran Affairs medical centers (Engelhardt et al., 2006). The remaining studies are observational; three non-randomised controlled designs (Teo et al., 2014; Baker et al., 2012 and Yoo et al., 2012) and ten natural experiments.

Study samples

The studies are based on a wide variety of samples. Three studies use data from the US Health and Retirement Study, with its nationally representative sample of older people (Nicholas et al., 2014; Nicholas et al., 2011; Kelley et al., 2011), while Kessler and McClellan (2004) use a large random sample of Medicare beneficiaries. The remaining studies use selective samples, defined either by patient characteristics, for example, high-cost and low-income Medicare beneficiaries (Hamlet et al., 2010), or by care setting, with seven of the studies based on hospital samples (Yoo et al., 2012; Tan and Jatoi, 2011; Zhang et al., 2008; Gade et al., 2008; Teno et al., 1997; Weeks et al., 1994; Chambers et al., 1994). Some studies use samples defined by both patient characteristics and care setting, for example, patients admitted to an inpatient oncology unit in a US hospital (Tan and Jatoi, 2011). While selective samples are appropriate for evaluating interventions specific to these populations and settings, care needs to be taken in generalising findings to individuals beyond these groups. Hospital sam-

ples, for example, are likely to over-represent those who are least able to die at home (Wholihan, 2012). Sample sizes range from under 50 (Baker et al., 2012) to around 3000 or more (Nicholas et al., 2014; Nicholas et al., 2011; Kelley et al., 2011; Hamlet et al., 2010; Teno. et al., 1997), with one study, looking at the economic impact of state level laws incentivising compliance with the Patient Self Determination Act (1990), with a sample of over 75,000.

Definition of ACP

Of the 18 included studies, eight are non-intervention studies, exploring the impact of ACP in general. These cover different types of ACP activity, operationalised for research in a range of ways (Table 2).

Table 2: Operational definition of ACP in general (non-intervention) studies

Nicholas et al., 2014	A proxy report of a decedent having a treatment-limiting, written AD; US Health and Retirement Study
Nicholas et al., 2011	A proxy report of a decedent having a treatment-limiting, written AD; US Health and Retirement Study
Kelley et al., 2011	A proxy report of a decedent having a written AD or having engaged in an end of life discussion; US Health and Retirement Study
Tan and Jatoi, 2011	Record of an AD completed prior to hospital admission in retrospectively reviewed medical records
Zhang et al., 2008	Self-report during baseline interview of having had a prior discussion with their doctor about end of life preferences.
Kessler and McClellan, 2004	State with laws enhancing incentives for compliance with Patient Self-Determination Act (PSDA,1990)
Weeks et al., 1994	Record of an AD completed prior to a terminal hospital admission in retrospectively reviewed medical records
Chambers et al., 1994	Record of an AD entered into patient notes within 48 hours of terminal hospital admission in retrospectively reviewed medical records

These general ACP studies, except for Zhang et al. (2009), rely entirely on secondary data sources and provide limited information about the process of ACP, such as when and how ACP was first initiated, whether ACP was facilitated by a trained professional or the frequency of review, factors known to influence the quality and effectiveness of ACP (Brinkman-Stoppelenburg et al., 2014; Detering et al., 2010; Lorenz and Lynn, 2004; Ng and Chong, 2013). The quality of ADs cannot be presumed to be always high, with Tan and Jatoi (2011) noting that around a third of the 46 ADs held by patients in their study were insufficiently specific. Several studies attempt to distinguish ACP from the documenting of medical decision-making in the last weeks and days of life, with two studies specifying that ADs should have been initiated prior to the index hospital admission (Weeks et al., 1994; Tan and Jatoi, 2011). Weeks et al. (1994) also gather data about when these ADs were first established, finding it to be a median of eight months prior to hospital admission. Zhang et al. (2009) similarly require that end of life discussions with a physician should have occurred prior to study enrolment, with participants enrolled onto the study an average of 6 months prior to death.

The remaining ten studies focus on specific interventions designed to promote ACP, (Table 3). These are varied, but are most commonly counselling and support services, generally led by nurses and social workers, with the aims, variously, of promoting and supporting ACP, assisting in end of life decision-making and optimizing patient-physician communication. When delivered as part of a wider intervention, these involve additional measures to identify and address unmet support needs. They may involve specialist palliative care physicians and nurses, and commonly allow for referral to other specialist services.

Table 3: Description of ACP interventions for included intervention studies

Teo et al., 2014	Project CARE, a nursing home-based ACP and palliative care intervention in Singapore. Residents at risk of dying within 6-12 months are approached to complete an ACP, nursing home staff receive training and hospital-based physicians and nurses make regular visits.
Abel et al., 2013	A hospice in the South West of England, where preferred place of death is routinely discussed and recorded in an electronic patient record

Lukas et al., 2013	Optimising Advanced Complex Illness Support (OACIS), a home-based, non-hospice palliative programme in the US. Nurse practitioners, supported by physicians, undertake an initial 1-2 hour consultation, complete a 'goals of care' transcript, assist the patient to complete an AD where appropriate, and undertake follow-up visits. Nurse practitioners actively liaise with primary care physicians and managing specialists and make referrals to other services.
Baker et al., 2012	Intensive case management and ACP undertaken with patients identified as being at increased risk of hospital admission in a Scottish general practice. An extended primary care team of case managers, a physiotherapist, an occupational therapist and care workers address unmet support needs, including through referral to other services. The programme includes rapid provision of home care and hospital-to-home transport.
Yoo et al., 2012	Integrated palliative care service, embedded within an intensive care unit (ICU) in a US hospital, with the aim of facilitating communications between health professionals and patients or families.
Hamlet et al., 2010	Telephone-based intervention in the US, where each patient has a designated nurse trained in end of life counselling. Sessions cover counselling about ADs, choice of aggressive vs palliative care and hospice enrollment. The nurse also facilitates interaction with physicians and hospice agencies or make other referrals as required.
Gade et al., 2008	Integrated Palliative Care Service (IPCS) teams, in three US hospitals, including a palliative care physician, palliative care nurse, hospital social worker and chaplain. The teams assess patients' need for symptom management, psychosocial and spiritual support, end-of-life planning and post-discharge care, and organise relevant follow-up and referrals. The discharge plan is communicated to primary care physicians via an electronic patient record.
Engelhardt et al., 2006	Advanced Illness Coordinated Care Program (AICCP), delivered in a series of healthcare settings over six sessions by a care coordinator. Sessions may cover a wide range of issues including ACP, completion of ADs, health literacy, preparing questions for physician appointments, care coordination and referrals, addressing emotional and psychological needs, family communication etc.
Molloy et al., 2000	Let Me Decide AD programme in three nursing homes, involving education for hospital and nursing home staff about ADs and facilitation of ACP with patients and/or families of nursing home residents.
Teno et al., 1997	The SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), conducted in five teaching hospitals in the US, including an intervention in which trained nurses had multiple contacts with patients, families, physicians and hospital staff to elicit preferences, improve understanding of outcomes, facilitate ACP and physician-patient communication.

Although ADs and other advance care plans are only operable when a patient loses capacity, none of the 18 studies limit their definition of ACP to these situations. Exceptionally, Weeks et al. (1994) report the number of patients who lost capacity and had their AD ‘activated’ but note that patients with ADs do not lose capacity frequently enough for this to lead to significant healthcare savings. In practice, all of the studies assume that ACP can lead to healthcare savings for patients who do not lose capacity, but the mechanisms by which this is achieved are not well articulated. Weeks et al. (1994) suggest that engagement in ACP may enable patients to develop and better articulate their views on care priorities or the presence of an AD in medical notes may influence the care and treatment that physicians propose. However, none of the studies operationalise or test such hypotheses.

Cost measurement

No cost-effectiveness studies, involving the systematic identification of costs and outcomes and the potential trade-offs between these, were identified. Rather, included studies can mostly be characterised as cost-savings studies, focused on identifying potential healthcare, and particularly hospital-based, cost savings. Healthcare costs, however, are defined and measured in a wide range of different ways (Table 3). Six of the studies use Medicare charges as their cost measure. Of these, Nicholas et al. (2014), Nicholas et al. (2011) and Kelley et al. (2011) use total Medicare charges, covering eligible care delivered in any setting. Hamlet et al. (2010) also use total Medicare charges, but exclude hospice care, while Kessler and McClellan (2004) use total Medicare charges but include co-payments and deductibles, additional costs that would normally be met by the patient, Medicaid or a Medigap supplementary or other insurance policy. Yoo et al. (2012) include charges to both Medicare and Medicaid but for hospital inpatient care only. Three of the studies use direct charges, made to the patient or their insurer (Weeks et al., 2004; Chambers et al., 2004; Teno et al., 1997), with adjustments made for different patient factors. Seven studies use accounting costs, using a range of different accounting systems, assumptions and approaches, and either covering hospital services alone (Lukas et al., 2013; Abel et al., 2013; Baker et al., 2012; Tan and Jatoi, 2011) or a wider set of healthcare costs (Teo et al., 2014; Gade et al., 2008; Engelhardt et al., 2006). Teo et al. (2014), additionally include nursing home costs, which they define as healthcare costs and are funded by the

Singapore Ministry of Health. Finally, two studies estimate costs using nationally calculated average unit costs (Zhang et al., 2008; Molloy et al., 2000).

Table 4: Operational definition of costs

General (non-intervention) studies	
Nicholas et al., 2014	Medicare expenditure in last 6 months of life.
Nicholas et al., 2011	Medicare expenditure in last 6 months of life.
Kelley et al., 2011	Medicare expenditure in last 6 months of life.
Tan et al., 2011	Total hospital costs using accounting costs adjusted for age at death and length of stay.
Zhang et al., 2008	Hospital costs for one week before death, estimated using the National (Nationwide) Inpatient Sample, based on a national 20 per cent random sample of hospital discharges.
Kessler and McClellan, 2004	Total Medicare claims, including co-payments and deductibles, for last month of life.
Weeks et al., 1994	Physician and hospital charges for terminal admission adjusted by diagnosis related groups.
Chambers et al., 1994	Hospital charges adjusted by a range of factors, including clinical and demographic factors.
Intervention studies	
Teo et al., 2014	Per patient nursing home costs are derived by dividing total budget by number of patient days. Hospital, primary and other healthcare costs are based on average charge per day or unit cost, provided by the nursing home group finance department. Intervention costs are estimated using fixed costs along with estimated activity multiplied by hourly staff costs. All estimates cover the last 3 months of life.
Abel et al., 2013	Actual costs of hospital treatment in last year of life adjusted for length of stay and complexity of care as per national agreement.

Lukas et al., 2013	Total and variable hospital accounting costs, estimated for the period 18 months pre-enrolment and compared to the period 18 months post-enrolment.
Baker et al., 2012	Costs of unplanned hospitalisations are calculated using an NHS local patient-level information and costing system (PLICS), with data gathered for three months prior to death for decedents and 12 months prior to, and following, the introduction of the intervention for survivors.
Yoo et al., 2012	Total Medicare and Medicaid charges for index hospital admission.
Hamlet et al., 2010	Total Medicare expenditure in last 6 months of life, excluding hospice care.
Gade et al., 2008	Health service costs calculated using accounting costs, based on agreed rate structure/ contract rates, and covering costs for emergency department, clinic, hospital outpatient, home health visits, hospital re-admissions, skilled nursing facility admissions and pharmacy. Intervention costs estimated using staff time and wages.
Engelhardt et al., 2006	Cost data for health services from participating Veteran Affairs medical centres cost records. Intervention costs calculated using contact time and salary for care coordinators and relevant overhead costs.
Molloy et al., 2000	Different healthcare interventions and services received by residents (covering hospital treatment, emergency department, physician consultations, outpatient services, diagnostic procedures, surgical operations and pharmacy) were monitored and the costs of these estimated using unit costs derived from the Government-led Ontario Case Costing Project and the Ontario fee schedule, Ontario Ministry of Health price list and the Ontario Drug Benefit formulary .
Teno et al., 1997	Hospital charges for index admission, adjusted by Therapeutic Intensity Scale Score (TISS) and length of stay.

The use of these different cost measures produces different figures, since they effectively measure different things. For example, charges made to Medicare are commonly lower than direct charges since Medicare does not cover all costs and is also able to negotiate volume discounts not available to individual health service users (Finkler,

1982). Charges may also be poorly aligned with underlying resource use (Finkler, 1982). For example, in an analysis of data from one UK hospital trust, Blunt and Bardsley (2012) found that costs for delivering services were often very different from the tariff price paid by NHS commissioners, with only 17 per cent of patients incurring costs that fell within 10 per cent of the tariff price. The most appropriate measure, therefore, depends on what it is intended exactly to measure and the economic perspective taken.

Hamlet et al. (2010) evaluate an intervention explicitly designed to identify cost savings to Medicare. Commonly, however, the economic perspective taken is not explicit; although is implied in the cost measures chosen, which, in all of the studies, are limited to healthcare costs. Eight of the studies include community-based as well as hospital costs (Teo et al., 2014; Nicholas et al., 2014; Nicholas et al., 2011; Kelley et al., 2011; Hamlet et al., 2010; Gade et al., 2008, Engelhardt et al., 2006; Kessler and McClellan, 2004), although, the range of included services varies and it is often unclear whether all possible healthcare services are covered. Ten of the studies include only, or primarily, hospital costs (Abel et al., 2013; Lukas et al., 2013; Baker et al., 2012; Tan and Jatoi, 2011; Yoo et al., 2012; Zhang et al., 2009; Molloy et al., 2000; Teno et al., 1997; Weeks et al., 1994; Chambers et al., 1994). Since reduced inpatient hospital care is likely to require substitution with community-based health and palliative care services (Yu et al., 2014; Kinley et al. 2014; Social Care Institute for Excellence, 2013; Emanuel and Emanuel, 1994), studies that focus only on hospital costs will fail to identify changes to these wider service costs.

None of the studies takes a societal perspective, with all non-healthcare costs omitted from analyses. However, fewer hospitalisations and hospital deaths are likely to have impacts for unpaid family and other carers (Social Care Institute for Excellence, 2013; Newman, 2013; Kelley et al., 2011; McCrone, 2009; Dumont et al., 2009). These may include negative impacts, for example, on carers' mental and physical health or their employment and finances (Funk et al., 2010) and on the total amount of unpaid care provided (Yu et al., 2014; McCrone, 2009). However, there may also be positive impacts, with ACP found in some studies to be associated with less depression and anxiety for carers (Detering et al., 2010; Wright et al., 2008). Reduced hospitalisation has also been associated with increased use of social care services in the UK

(Bardsley et al., 2012), although a follow-up study suggests these costs are unlikely to be high (Georghiou et al., 2014). Finally, the primary purpose of ACP is to improve people's quality of life and reduce avoidable distress. In economic evaluations, it is increasingly common to use a health-related quality of life measure to generate estimates of quality-adjusted life years (QALY) (Petrou and Gray, 2011; NICE, 2013), with the Palliative Care Yardstick (or PaLY) promoted by some as a potential alternative measure (Normand, 2009; Round, 2012; Hughes, 2005; Gomes, 2009). However, none of the studies include such measures. The limited reach of cost measurement is explicitly acknowledged by some authors (Hamlet et al., 2010; Weeks et al., 1994).

Intervention costs are also not always reported. Only four of the ten intervention studies report per-patient intervention costs (Teo et al., 2014; Gade et al., 2008, Engelhardt et al., 2006; Molloy et al., 2000), although Lukas et al. (2013) provide staffing and caseload information and Baker et al. (2012) provide an overall cost for the additional staffing required for the intervention. In the general ACP studies, we do not know whether or not patients received ACP facilitation and no costs for facilitation are included. The studies also vary in the period over which cost savings are measured, ranging from the last year (Abel et al., 2013) to the last week of life (Zhang et al., 2009), or not anchored by death at all, as in Baker et al. (2012), where costs are measured for a year post-intervention (Baker et al., 2012).

Controlling for confounding variables

Ethical and practical concerns mean that RCTs in end of life care research are difficult to implement (Higginson et al., 2013; Evans et al., 2014). Nonetheless, five studies (Hamlet et al., 2010; Gade et al., 2008; Englehardt et al., 2006; Molloy et al., 2000; Teno et al., 1997) use randomised designs. The remaining studies take steps, using multivariate regression analyses, propensity score matching or other statistical approaches, to control for confounding variables. Kelley et al. (2011) in their analysis of data from the Health and Retirement Study include age, gender, ethnicity, sex, education level, net worth, religiosity, self-rated health, having relatives nearby, marital status, residential status, type of non-Medicare insurance coverage (Medicaid,

Medigap or Veterans Administration), functional status, diagnosis and a range of regional variables. Other studies using Health and Retirement Study data additionally include factors such as cognitive status, comorbidities and alternative regional variables such as nursing home capacity (Nicholas et al., 2014; Nicholas et al., 2011). Other observational studies control for a similar range of demographic and risk-related variables (Teo et al., 2012; Yoo et al., 2012; Tan and Jatoi, 2011; Zhang et al., 2009; Weeks et al., 1994; Chambers et al., 1994). In the UK, Baker et al. (2012) selected intervention and control groups using a predictive model for identifying those at risk of hospitalisation. However, the control group was located nearby so the authors were unable to control for factors affecting the area-wide health system. Also, because so few patients died over the course of the study, the sample of decedents (where positive results were identified) was effectively unmatched. Abel et al. (2013), in a study using a selective sample of primarily cancer patients under the care of a UK hospice, control for fewest factors, indicating that the age and gender profile of the ACP and non-ACP group were similar.

Critically, in most of the observational studies, patient self-selection remains an important risk to validity, since it is possible, if not likely, that patients engaging in ACP may differ in their attitudes to dying or their perception of disease curability. They may also have doctors who favour less aggressive care or carers who are more supportive of the withdrawal of curative care in the late stages of illness (Weekes et al., 2010). Zhang et al. (2009), who found a positive association between ACP and hospital cost savings in the last week of life, is the only study to report primary data from patients and families. By using propensity score matching and data from interviews with patients and family, they are able to control for illness acknowledgement and treatment preferences. Unfortunately, the interview follows the occurrence of ACP (a prior discussion about end of life preferences with a physician), but is still conducted an average of 6 months before death.

The economic effects of ACP

Study findings are mixed, with little or no evidence that positive results are associated with whether the study is a general ACP or intervention study, the research design, sample size or setting. For example, of the eight studies that explore the impact of

ACP in general, just over half (five) report a statistically significant association between ACP and healthcare savings (Nicholas et al., 2014; Nicholas et al., 2011; Zhang et al., 2008; Weeks et al., 1994; Chambers et al., 1994). Of the ten intervention studies, exactly half (five) report a statistically significant association between the intervention and healthcare savings (Teo et al., 2014; Lukas et al., 2013; Hamlet et al., 2010; Gade et al., 2008; Molloy et al., 2000). With regard to research design, looking just at the five RCTs, just over half (three) report a statistically significant association between ACP and reduced healthcare costs (Hamlet et al., 2010; Gade et al., 2008; Molloy et al., 2000), while just over half (seven) of the 13 observational studies found a statistically significant association between ACP and reduced healthcare costs (Teo et al., 2014; Nicholas et al., 2014; Lukas et al., 2013; Nicholas et al., 2011; Zhang et al., 2009; Weeks et al., 1994; Chambers et al., 1994). There is also no apparent relationship between positive findings and sample size, although two studies that found no association had relatively small sample sizes and may have been under-powered (Tan and Jatoi, 2011; Engelhardt et al., 2006). Both nursing home-based studies found positive results (Teo et al., 2014; Molloy et al., 2000), however there was no clear pattern between positive results and other care-settings.

Because of the different measures, cost savings figures are not comparable between studies. However, figures ranged (unadjusted for inflation) from \$64,827 for the terminal hospitalisation of decedents in a US hospital (Chambers et al., 1994), through \$56,700 in total healthcare costs over six-months for high cost, low income Medicare beneficiaries (Hamlet et al., 2010) and \$11,500 over last six-months of life for decedents with dementia living in the community (Nicholas et al., 2014), to \$1041 in hospital costs over last week of life, for decedents with cancer (Zhang et al., 2009).

All of the studies with positive results (with the exception of Teo et al., 2014 and Hamlet et al., 2010, which measured only costs) found corresponding reductions in a range of associated outcomes. These covered reductions in the following: hospital death and ICU use (Nicholas et al., 2014); hospitalisations, length of stay and 30-day re-admissions (Lukas et al., 2013); hospital deaths (Nicholas et al., 2011); ICU admissions and aggressive treatments (Zhang et al., 2009); ICU use for patients re-admitted after the index hospitalisation (Gade et al., 2008); hospitalisations (Molloy et al., 2000); ICU use and major surgical treatments (Weeks et al., 1994) and ICU use, re-

duced length of stay and billable procedures (Chambers et al., 1994). Although the association between ACP and cost savings was less clear in the two UK studies, Baker et al. (2012) found that ACP was associated with reduced hospitalisations and length of hospital stay for a small sample of decedents, albeit compared with an effectively unmatched control group, and Abel et al. (2013) found that ACP was associated with reduced length of hospital stay in the last year of life, although not with a reduced number of hospital admissions.

5. Conclusion

Strengths and limitations

Our review covers 24 years, capturing research dating back to the introduction of the US Patient Self-Determination Act (1990). It is wide ranging, covering all populations and settings, and provides an overview of the range and heterogeneity of economic studies in this area. However, the review is also subject to a number of limitations. The small number of relevant studies, the lack of cost-effectiveness studies, the methodological limitations described and the fact that studies were highly heterogeneous, limit our ability to draw firm conclusions about the economic outcomes associated with ACP. It was also difficult to find an adequate search strategy given the diversity of the literature. Two studies were identified outside of the main search, one through a review of references and one independently known to the authors. It is also possible that we missed some relevant articles that did not refer to ACP in the abstract. However, the supplementary search of PubMed based on the MESH term ‘advance care planning’ identified no further relevant studies, providing some confidence that our initial search strategy was sufficiently rigorous. We included studies where ACP was a significant part of a wider intervention, thus overlapping with a broader literature on palliative care and end of life interventions. Some of these may include an element of ACP, but where ACP is not referred to in the title, abstract or key words we have assumed it to be a less substantial aspect of an intervention.

Summary and conclusion

Overall, evidence on the economic implications of ACP is limited and equivocal. However, the literature includes some well-conducted studies that find a statistically significant association between ACP (or interventions involving ACP facilitation as a significant element) and healthcare savings. In particular, there is evidence that ACP is associated with healthcare savings for some people in some circumstances, including people living in nursing homes (Teo et al., 2014; Molloy et al., 2000), with high support needs and low income (Hamlet et al., 2010), living with dementia in the community (Nicholas et al., 2014) or living in a high-spending healthcare region (Nicholas et al., 2011).

The vulnerability of observational studies to selection bias, particularly self-selection bias, is a significant challenge for research in this area. Brinkman-Stoppelenburg et al. (2014), in their systematic review of the (non-economic) effects of ACP on end of life care, consequently call for more experimental designs, with Halpern and Emanuel (2012) proposing cluster RCT designs, to address some of the ethical challenges associated with experimental research. However, our review suggests that the challenges are not just those of managing selection biases, although this is important. The complexity of ACP, the need to better understand the mechanisms linking ACP to healthcare savings and the potential for identifying and targetting populations and circumstances with the greatest potential for cost-effectiveness gains suggests a need for more mixed methods research (Higginson et al., 2013). This could include the use of realist approaches, which aim to make explicit and test causal pathways and are particularly suitable for evaluating complex interventions (Pawson and Tilley, 1997). There is also a need to ensure that the design and implementation of ACP interventions in practice are effective (Lynn et al., 2000), suggesting a role for developmental research, implementation research and process evaluation.

Finally, the identified studies focus exclusively on healthcare cost savings, potentially lending support to the view that interest in ACP is driven by a search for short-term cost savings (Halpern and Emanuel, 2012). Research into the economic implications of ACP would benefit from a longer-term perspective, with an emphasis not just on the impact on costs but also on cost-effectiveness, with more research undertaken to understand the impact on unpaid carers, greater consideration given to substitute

community-based care and efforts made to include quality of life benefits. While it can appear that policy makers and commissioners are interested in making cost savings, what they are generally trying to do is contain costs within the constraints of available budgets and allocate resources in ways that are efficient and equitable. It is important to develop further evidence on the economic implications of ACP to support policy-makers and commissioners in this task and to help ensure appropriate investment in end of life care services.

REFERENCES

Department of Health. *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*. Department of Health, UK, July 2008.

Scottish Government. *Living and dying well: A national plan for palliative and end of life care in Scotland*. Report, Scottish Government, UK, September 2008.

Department of Health, Social Services and Public Safety (Northern Ireland). *Living Matters, Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland*. Report, Department of Health, UK, July 2010.

Brinkman-Stoppelenburg A, Rietjens JA and Van Der Heide A. The effects of advance care planning on end of life care: a systematic review. *Palliat Med* 2014; 28: 1000-1025.

General Medical Council. *Treatment and care towards the end of life: good practice in decision making*. Report, General Medical Council, UK, 2010.

Marckmann, G. and In Der Schmitzen, J. The Economics of Advance Care Planning: Empirical Data and Ethical Implications. *BMJ Support Palliat Care* 2013; 3: 241.

Centre for Reviews and Dissemination. *Systematic Reviews: CRD's guidance for undertaking systematic reviews in health care*. York: University of York, 2009.

Maksoud A, Jahnigen D W and Skibinski C I. Do not resuscitate orders and the cost of death. *Arch Intern Med* 1993; 153: 1249-1253.

Fonk J, Davidoff D, Lutzow T, et al. The Effect of Advance Directives on End of life Cost Experience. *J Health Care Poor Underserved* 2012; 23: 1137–1156.

Lisk R, Nari R and Yeong K. Geriatrician Input Into 12 Care Homes Reduced Emergency Hospital Admissions Which Was Maintained With Education & Training Of GPs And Care Home Staff. *Age Ageing* 2014; 43(suppl1): i13–i13.

Gade G, Venohr I, Conner D, et al. Impact of an inpatient palliative care team: a randomized control trial. *J Palliat Med* 2008; 11:180-90.

Baker A, Leak P, Ritchie LD, et al. Anticipatory care planning and integration: A primary care pilot study aimed at reducing unplanned hospitalization. *Br J Gen Pract* 2012; 62: e113-e120.

Higginson IJ, Finlay I, Goodwin DM, et al. Do hospital-based palliative teams improve care for patients or families at the end of life? *J Pain Symptom Manage* 2002; 23: 96–106.

Abel J, Pring A, Rich A, et al. The impact of advance care planning of place of death, a hospice retrospective cohort study. *BMJ Support Palliat Care* 2013; 3: 168–173.

Molloy DW, Guyatt GH, Russo R, et al. Systematic implementation of an advance directive program in nursing homes, a randomized controlled trial. *JAMA* 2000; 283: 1437–1444.

Teo WS, Raj AG, Tan WS, et al. Economic impact analysis of an end of life programme for nursing home residents. *Palliat Med* 2014; 28: 430–437.

Hamlet KS, Hobgood A, Hamar GB, et al. Impact of predictive model-directed end of life counseling for Medicare beneficiaries. *Am J Manag Care* 2010; 16: 379–384.

Engelhardt JB, McClive-Reed KP, Toseland RW, et al. Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: a randomized trial. *Am J Manag Care* 2006;12: 93–100.

Teno J, Lynn J, Connors AF Jr, et al. The illusion of end of life resource savings with advance directives. *J Am Geriatr Soc* 1997; 45: 513–518.

Yoo JW, Nakagawa S and Kim S. Integrative palliative care, advance directives, and hospital outcomes of critically ill older adults. *Am J Hosp Palliat Care* 2012; 29: 655–662.

Nicholas LH, Bynumm JP, Iwashynam TJ, et al. Advance directives and nursing home stays associated with less aggressive end of life care for patients with severe dementia. *Health Aff (Millwood)* 2014; 33: 667–74.

Nicholas LH, Langa KM, Iwashyna TJ et al. Regional variation in the association between advance directives and end of life Medicare expenditures. *JAMA* 2011; 306: 1447–1453.

Kelley AS, Ettner SL, Morrison RS, et al. Determinants of medical expenditures in the last 6 months of life. *Ann Intern Med* 2011; 154: 235–242.

Kessler DP and McClellan MB. Advance directives and medical treatment at the end of life. *J Health Econ* 2004; 23: 111–127.

Tan TS and Jatoi A. End of life hospital costs in cancer patients: do advance directives or routes of hospital admission make a difference? *Oncology* 2011; 80: 118–22.

Zhang B, Wright AA, Huskamp HA, et al. Health Care Costs in the Last Week of Life Associations With End of life Conversations. *Arch Intern Med* 2008; 169: 480–488.

Weeks WB, Kofoed LL, Wallace AE, et al. Advance directives and the cost of terminal hospitalization. *Arch Intern Med* 1994; 18: 2077–2083.

Chambers, CV, Diamond JJ, Perkel RL, et al. Relationship of advance directives to hospital charges in a Medicare population. *Arch Intern Med* 1994; 154: 541–547.

Wholihan D. and Pace J. Community Discussions: A Vision for Cutting the Costs Of

End of life Care. *Nurs Econ* 2012; 30:170-175.

Detering KM, Hancock AD, Reade MC, et al. The Impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *BMJ (Clinical research ed.)* 2010; 340: c1345.

Lorenz KA and Lynn J. Oregon's lessons for improving advance care planning. *J Am Geriatr Soc* 2004; 52: 1574–5

Ng R and Chong R. Perceptions of benefits and barriers in conducting advance care planning: A cross-sectional survey of trained advance care planning facilitators. *BMJ Support Palliat Care* 2013; 3: 279

Lukas L, Foltz C and Paxton H. Hospital Outcomes for a Home-Based Palliative Medicine Consulting Service. *J Palliat Med* 2013; 16: 179–184.

Finkler SA. The distinction between cost and charges. *Ann Intern Med* 1982; 96:102-109.

Blunt, I. and Bardsley, M. *Patient-level costing: can it yield efficiency savings?* Report, Nuffield Trust, UK, September 2012.

Yu M, Guerriere DN, Coyte PC. Societal costs of home and hospital end-of-life care for palliative care patients in Ontario, Canada. *Health Soc Care Community*. 2014 Dec 2. doi: 10.1111/hsc.12170. [Epub ahead of print]

Kinley J, Hockley J, Stone L, et al. The provision of care for residents dying in UK nursing care homes, *Age Ageing*, 2014, 43; 375-379

Social Care Institute for Excellence. *Dying well at home: the case for integrated working*. Report, SCIE Guide 48, UK, May 2013.

Emanuel E and Emanuel L. The economics of dying: the illusion of cost savings at the end of life. *N Engl J Med* 1994; 330: 540-544.

Newman, R. Palliative Care Funding Review: Implications for family carers. *End of Life Journal* 2013; 3: 1–4.

McCrone P. Capturing the Costs of End-of-Life Care: Comparisons of Multiple Sclerosis, Parkinson's Disease, and Dementia. *J Pain Symptom Manage*. 2009; 38 (1): 62 - 67

Dumont S, Jacobs P, Fassbender K, et al. Costs associated with resource utilization during the palliative phase of care: a Canadian perspective. *Palliat Med*, 2009; 23: 708-717.

Funk, L., Stajduhar, K., Toye, C., et al. Part 2: home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008). *Palliat Med*, 2010, 24: 6: 594–607.

Wright AA, Zhang B, Ray A, et al. Associations between end of life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*, 2008; 300:1665-1673.

Bardsley, M, Georghiou T, Davies S and Davies A. *Understanding patterns of health and social care at the end of life*, Report, Nuffield Trust, UK, October 2012.

Georghiou T and Bardsley M. *Exploring the cost of care at the end of life*, Report, Nuffield Trust, UK, September 2014

Petrou S and Gray A. Economic evaluation using decision analytical modelling: design, conduct, analysis, and reporting, *BMJ*. 2011 Apr 11;342: d1766.

National National Institute for Health and Clinical Excellence (NICE), *Guide to the methods of technology appraisal*, National Institute for Health and Clinical Excellence, UK, April 2013.

Normand C. Measuring outcomes in palliative care: Limitations of QALYs and the road to PaLYs. *J Pain Symptom Manage* 2009; 38: 27–31.

Round J. Is a QALY still a QALY at the end of life?. *J Health Econ* 2012; 31: 521-527

Hughes J. Palliative care and the QALY problem. *Health Care Anal* 2005; 13: 289-301.

Gomes B, Harding, R and Foley M, et al. Optimal Approaches to the Health Economics of Palliative Care: Report of an International Think Tank. *J Pain Symptom Manage* 2009; 38: 4-10.

Higginson I, Evans, C, Grande G, et al . on behalf of MORECare. 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 Med* 2013; 11: 111.

Evans C, Stone K, Manthorpe J, et al. *MRC guidance on developing and evaluating complex interventions: Application to research on palliative and end of life care*. Report, School for Social Care Research, Methods Review 15, National Institute for Health Research. London, UK, 2013.

Goodman C, Froggatt K and Mathie E. *End of Life Care*. Report, School for Social Care Research, Methods Review 12, National Institute for Health Research. London, UK, 2012.

Halpern S D and Emanuel, E J. Advance directives and cost savings; Greater clarity and perpetual confusion. *Arch Intern Med* 2012; 172: 266-268.

Lynn J, DeVries KO, Arkes HA, et al. Ineffectiveness of the SUPPORT intervention: review of explanations. *J Am Geriatr Soc*. 2000;48(suppl 5):S206-S213.

Pawson R. and Tilley, N. *Realist evaluation*. London: SAGE Publications Ltd,1997.