ORIGINAL ARTICLE



Exploring the cost-effectiveness of advance care planning (by taking a family carer perspective): Findings of an economic modelling study

Annette Bauer MSc | Josie Dixon MSc | Martin Knapp PhD | Raphael Wittenberg MSc |

Care Policy and Evaluation Centre (CPEC), London School of Economics and Political Science, London, UK

Correspondence

Annette Bauer, Care Policy and Evaluation Centre (CPEC), London School of Economics and Political Science, Houghton Street, London WC2A 2AE, UK. Email: a.bauer@lse.ac.uk

Funding information

This work was produced for and funded by the National Institute for Health and Care Excellence for the national social care guideline 'Decision making and mental capacity' (NG108).

Abstract

Advance care planning is considered an important part of high-quality end-of-life care. Its cost-effectiveness is currently unknown. In this study, we explore the costeffectiveness of a strategy, in which advance care planning is offered systematically to older people at the end-of-life compared with standard care. We conducted decision-analytic modelling. The perspective was health and social care and the time horizon was 1 year. Outcomes included were quality-adjusted life years as they referred to the surviving carers. Data sources included published studies, national statistics and expert views. Average total cost in the advance care planning versus standard care group was £3,739 versus £3,069. The quality-adjusted life year gain to carers was 0.03 for the intervention in comparison with the standard care group. Based on carer's health-related quality-of-life, the average cost per quality-adjusted life year was £18,965. The probability that the intervention was cost-effective was 55% (70%) at a cost per quality-adjusted life year threshold of £20,000 (£30,000). Conducting cost-effectiveness analysis for advance care planning is challenging due to uncertainties in practice and research, such as a lack of agreement on how advance care planning should be provided and by whom (which influences its costs), and about relevant beneficiary groups (which influences its outcomes). However, even when assuming relatively high costs for the delivery of advance care planning and only one beneficiary group, namely, family carers, our analysis showed that advance care planning was probably cost-effective.

KEYWORDS

advance care planning, cost-effectiveness, decision analysis, economic evaluation, end-of-life care, modelling, older people

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2020 The Authors. Health and Social Care in the Community published by John Wiley & Sons Ltd

1 | BACKGROUND

The important role of advance care planning (ACP) as part of highquality end-of-life care is highlighted in the current policy and research discourse (Carr & Luth, 2017; Department of Health, 2015; Mullick, Martin, & Sallnow, 2013; NICE, 2018). In ACP, people at risk of losing the capacity to communicate in the foreseeable future are supported by health and social care professionals to formally set out their goals and preferences for future treatment and care (Rietjens et al., 2017). In practice, ACP is provided differently in a range of different settings. An important target population of ACP are older people approaching end-of-life.

As is the case for many complex interventions, ACP is expected to achieve multiple outcomes for multiple beneficiaries. For example, in a recent international study (Dixon & Knapp, 2019), representatives from a range of health and care organisations reported various, often closely interlinked goals for and benefits of ACP. Some of those related to the person dying, their family carers or staff, others to broader organisational goals such as making best use of resources, optimising care and avoiding legal complaints from bereaved families, and associated reputational and financial losses.

Commonly evaluated outcomes for ACP include those that measure the compliance with patient wishes or preferences about treatment (e.g. not to apply life-prolonging treatments) or place of death. These outcomes matter not only to many patients and family carers (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013) but also to hospitals and other health and care organisations, which seek to optimise care while containing costs. Findings from those studies consistently suggest that ACP can effectively change these outcomes in the expected direction (Abel, Pring, Rich, Malik, & Verne, 2013; Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014; Detering, Hancock, Reade, & Silvester, 2010; Dixon, King, & Knapp, 2019; Nicholas, Bynum, Iwashyna, Weir, & Langa, 2014; Wright et al., 2008; Zhang et al., 2009).

The impact of ACP on (mental) health outcomes for patients and family carers (from now on referred to as carers) is less well established. Different mechanisms have been suggested by which ACP might positively or negatively affect the quality-of-life of the person dying and of their carer. While ACP can be a distressing and negative experience for some, others perceive it as a process that helps them to feel more in control (Zwakman et al., 2018). Since ACP reduces the chance for a person to receive aggressive, life-prolonging treatments, it potentially reduces the likelihood of major depressive disorders for patients and carers linked to those treatments (Brinkman-Stoppelenburg et al., 2014; Wright et al., 2008; Zhang et al., 2009). The few evaluations of ACP, which specifically measure quality-of-life of the person approaching endof-life, do so by asking their carers or professionals rather than persons themselves (who might not be well enough to respond; Wright et al., 2008). The validity of such proxy outcomes and the methodological robustness of measuring quality-of-life in people

What is known about this topic?

- Advance care planning (ACP) has been associated with a range of positive outcomes for different beneficiaries – including for family carers.
- It is also associated with reductions in life-prolonging treatments and hospital deaths.
- Knowledge of the cost-effectiveness of ACP is lacking.

What this paper adds?

- This study is the first to explore the cost-effectiveness of a strategy, in which ACP is offered to all older people at the end-of-life.
- Our findings suggest an economic argument for scaling ACP; however, this strongly depends on how ACP is delivered and implemented in practice.
- Findings from this study informed together with other evidence – national recommendations in England about the provision of ACP.

approaching end-of-life have been questioned (Albers et al., 2010; Zhang et al., 2009).

Measuring quality-of-life for family carers does not bear the same challenges. One of the few randomised controlled trials in this area (Detering et al., 2010) found significantly lower depression and anxiety scores in carers of people who were offered ACP compared to those who were not. Similar findings have been confirmed by other studies, which showed improvements in quality-of-life or reductions in major depressions of carers including after the death of the person they cared for (Brinkman-Stoppelenburg et al., 2014; Detering et al., 2010; Wright et al., 2008).

From a health organisation as well as government perspective, it is important that interventions are cost-effective and affordable. Two recent systematic reviews of economic evidence found that ACP had the potential to reduce costs, which was primarily due to the lower use of hospital and intensive care (Dixon, Matosevic, & Knapp, 2015; Klingler, in der Schmitten, & Marckmann, 2016). However, the majority of evidence was from the US, and it is not clear how applicable those findings are to other countries, including England where – for example – the pressure for hospitals to reduce life-prolonging treatments might be different. In addition, most studies did not include the costs of care in the community. Importantly, none of the studies measured cost-effectiveness, that is, changes in total costs in relation to changes in health outcomes (Dixon, Matosevic, et al., 2015; Klingler et al., 2016).

Overall, research on ACP, including the impact it has on patients and carers, and its cost-effectiveness, has been criticised as fragmented and relatively low quality with only very few studies using experimental designs (Dixon & Knapp, 2019; Gomes et al., 2013). This is partly due to the nature of ACP, which is a

complex intervention that is provided differently in different settings (Brinkman-Stoppelenburg et al., 2014; Gomes et al., 2013). However, even in the absence of robust evidence, governments still need to make decisions about whether or not to facilitate the scaling of ACP especially as health and social care systems face a substantial spending rise on end-of-life care due to population ageing.

In the light of limited evidence, the aim of this study was to simulate the likely cost-effectiveness of a strategy, in which ACP is systematically offered to older people reaching end-of-life compared with standard care. While, in practice, ACP is a complex, personalised process that might be provided during the course of several meetings and differs based on contextual and individual factors, this study sought to reflect the range of practice. The work was conducted to help inform discussions by experts, who had the task to develop recommendations for a national guideline in England (NICE, 2018).

2 | METHODS

2.1 | Overview

We developed a decision-analytic model in Microsoft Excel 2013 to explore the likely cost-effectiveness of a strategy in which ACP was offered, compared with standard care, in a hypothetical cohort of older people (mean age 85 years) approaching end-of-life. The mean age was chosen as it reflected the average age of individuals when they were offered ACP according to studies of ACP (e.g. Detering et al., 2010). ACP referred to an organised strategy, in which relevant staff were trained to provide ACP and offer it to older people (and their family carer) who had mental capacity and were reaching the end-of-life. The definition for end-of-life was taken from the National Institute for Health and Care Excellence (NICE), which defines it as care provided to adults with advanced, progressive, or incurable conditions, and who are expected to die within the next 12 months (NICE, 2011a). We, thus, assumed that ACP was provided in the last year of life.

Decision-analytic modelling is a method, in which data from multiple sources are combined to demonstrate pathways of events, and the associated costs and health outcomes that occur as a result of a decision (here: whether or not to invest in a ACP strategy). It is used in situations, in which there is substantial uncertainty about costs and outcome linked to competing courses of actions.

The perspective was health and social care. Costs related to those met by the health and social care sectors. More specifically, they referred to the cost of offering ACP in line with good practice, costs linked to the provision of life-prolonging treatment (in form of cardiopulmonary resuscitation and assisted ventilation) and costs for end-of-life care at home versus in hospital. All costs were presented in 2016 Great British Pounds. If unit costs were not available for 2016, they were inflated using the Hospital and Community Health Services Index.

Health outcomes referred to quality-adjusted life years (QALYs) gained by the family carer rather than the person dying. This was done because of the methodological challenges of including quality-of-life for the person dying and because health and well-being outcomes of carers are increasingly recognised, legally and policy wise, as an important secondary outcome as well as an important outcome in their own right when assessing the effectiveness of technologies or interventions. For example, NICE requested the inclusion of carers' health quality-of-life alongside patient's health-related quality in their guideline for people with dementia (NICE, 2009).

Findings were presented in the form of incremental cost-effectiveness ratios (ICER), which we calculated by dividing the differences in costs by differences in QALYs. In order to judge the likely cost-effectiveness of ACP we applied cost per quality-of-life year thresholds of £20,000 and £30,000, which are commonly used in England.

Discounting was not necessary as the model covered a time horizon of 1 year, although it was difficult to define the time horizon exactly because there was uncertainty in the literature as to when ACP could or should happen, and as to when benefits to carers would occur. However, even if the benefit to the carer occurred after 1 year, discounting by 3.5% for 1 year would make very little difference to the findings. No longer-term costs or consequences beyond this period were expected.

2.2 | Data sources

Data to estimate resource use and health outcomes were sourced from published studies and national statistics. The main source for effectiveness data was a randomised controlled trial (RCT) conducted in Australia (Detering et al., 2010). Data drawn from this study included: treatment wishes recorded and followed, and mental health symptoms of carers. Another source of effectiveness data was a retrospective, observational study from England, which provided relative risks for people who received ACP of dying in the community and not in hospital (Dixon et al., 2019). For people in the standard care group, data - where possible - were taken from published national sources to increase relevance to the national context (Bardsley, Georghiou, Spence, & Billings, 2019; BHF, 2014; NCEPOD, 2012; Nolan et al., 2007; ONS, 2016; RCP, 2016; Sandroni, Nolan, Cavallaro, & Antonelli, 2007). Where this was not possible data were from the Australian RCT (Detering et al., 2010). Unit costs were taken from recognised national sources (Curtis & Burns, 2016; DHSC, 2016), or, where this was not possible, from other reliable sources (Georghiou & Bardsley, 2014; NICE, 2011b; Petrie et al., 2015). Health utility weights for mental health problems were taken from survey data of a representative sample of the general adult population in England (Roberts, Lenton, Keetharuth, & Brazier, 2014). The lead author worked in close collaboration with experts (the guideline committee) on the development of the model. They provided information on what good practice ACP should comprise and the resource inputs required to provide it.

2.3 | Model structure

The model structure was a simple decision tree. This was appropriate since the time horizon was short, the number of relevant events was limited and events were not repetitive (i.e., they only happened once towards the end-of-life). A separate sub-tree was developed for each consequence: use of life-prolonging assisted ventilation; use of life-prolonging cardiopulmonary resuscitation and use of end-of-life care for those dying in home instead of in hospital. Costs for the intervention and standard care groups were aggregated across the sub-trees and cost of delivering ACP added to the intervention group. This was then compared with the difference in QALYs for carers in the ACP versus standard care group. More details on the method can be found in the technical report produced for the guideline (NICE, 2017). All model parameters, values, their ranges and sources used for the modelling are presented in Tables 1–3.

2.4 | Estimating costs of delivering ACP

There are different practices of how ACP is delivered, which depend on national or local systems, organisational and individual factors. Since we sought to examine the cost-effectiveness of ACP reflecting a range of approaches (rather than one specific approach), we consulted with the experts who were part of the guideline committee on common steps involved in the delivery of ACP. Details about the consultation process are shown in Box 1. We asked them to estimate probabilities for different professionals from different disciplines to be involved, and to estimate durations for conducting the activities. For both, probabilities and durations, they were asked to estimate average, lower and upper estimates. We multiplied the duration of the activities by the relevant hourly costs for different staff. The cost for training staff to provide ACP was added. This included cost of a standard course and the opportunity costs for the time that staff attended the training. An assumption was made about the number of times ACP could be delivered before refresher training was required.

2.5 | Estimating cost consequences

Graph 1 shows the model structure for evaluating the cost consequences linked to cardiopulmonary resuscitation and assisted ventilation, which are the most common types of life-prolonging treatment in the general population of older people. Cost consequences were only applied to people for whom those types of life-prolonging treatments were expected to become medically relevant. Unit costs were assigned to the two types of life-prolonging treatments. This included the costs of a stay in an intensive care unit (ICU). For cardiopulmonary resuscitation, the unit cost reflected a weighted average with and without admission to an ICU. For assisted ventilation, it was assumed that an admission to an ICU was always required.

Next, the cost consequences of end-of-life care in different places of death (hospital; home; care home and hospice) were modelled for

the ACP and standard care groups. A complication was that the only study (Dixon et al., 2019), which measured the impact of ACP on place of death based on a nationally representative sample, did not include hospice as a place of death. While only few people die in hospice, it is a costly service, and there is evidence that ACP increase the probability for someone to die in hospice (Detering et al., 2010). Data were adjusted to include the probability of death in this setting; calculations conducted for the adjustment are shown in Box 2. Unit costs were assigned to different places of death. The average length of a final hospital episode for people dying in hospital was used as the unit for costing the care provided in the other places (hospice, home and care home). The cost of the care package for people dying in their home was based on resource inputs from a national report on end-of-life care (MarieCurie, 2012). Details on calculating the costs are presented in Appendix S1.

2.6 | Estimating effectiveness

We estimated the difference in health-related quality-of-life for family carers of people who were offered ACP versus those not offered ACP, which was due to the effect ACP has on their mental health. These calculations are illustrated in Graph 2. We took estimates from Detering et al. for the probabilities that family carers developed mental health problems (anxiety or depression) in the two groups and the average durations they experienced those symptoms. The study by Detering et al. measured carers' outcomes only at one time, which reflected a 6 months follow-up. It is possible that some people experienced a shorter episode of anxiety or depression and it is also possible that people experienced depression or anxiety for longer than 6 months. Conservatively, 6 months was taken as a maximum period over which the carer might have experienced depression and/ or anxiety. An estimate of 4 months was taken as a minimum value, and 5 months as an average value.

Health utility values were assigned to health states. Health utility data were taken from the Adult Psychiatry Morbidity Survey, which surveys a representative sample of the general population in England (Roberts et al., 2014). In Roberts et al. health state utility values were measured by SF-6D and EQ-5D indices and included those for anxiety, depression and mixed anxiety and depression. Both indices are valid tools for measuring health utilities, which strongly correlate with the Hospital Anxiety and Depression Scale (HADS; Jutte, Needham, Pfoh, & Bienvenu, 2015). In Roberts et al., the SF-6D was derived from individual responses to the SF-12 and the EQ-5D was derived by mapping from SF-12 items using a response approach mapping. Since this study contributed to a NICE guideline, and NICE prefers the use of the EQ-5D as a measure of health utility (in order to ensure comparability across guidelines), we took EQ-5D values for this study.

A complication was that data from the RCT from which data were derived (Detering et al., 2010) presented probabilities for developing anxiety and depression separately. Since those conditions are frequently co-occurring, calculations were conducted assuming a zero overlap and a 100% overlap between the conditions; and the

TABLE 1 Parameters, values (ranges), sources and details for estimating costs of delivering ACP and cost consequences linked to cardiopulmonary resuscitation (CPR) and assisted ventilation (AV)

	Mean or		
Parameter	deterministic value	Range	Source and details
Parameters for estimating cost of delivering ACF)		
Durations of process (in hours)			
Identification	0.13	0.02-0.25	Expert consultation
Mental capacity assessment	1.75	1-2.5	Expert consultation
ACP discussions	4.08	0.17-8	Expert consultation
Probabilities for professionals to be involved (in	%)		
During identification			
Care coordinator	100	-	Expert consultation
Advocate	15	5-25	Expert consultation
During mental capacity assessment			
Care coordinator	100	-	Expert consultation
During ACP discussions			
Care coordinator	100	-	Expert consultation
Medical consultant	50	25-100	Expert consultation
Advocate	13.5	2-25	Expert consultation
Solicitor (acting as Lasting Power of Attorney)	1.95	0.03-3.6	Expert consultation based on Beckett et al (2014)
Social Worker	40	20-60	Expert consultation
Occupational therapist	22.5	20-25	Expert consultation
Speech and language therapist	22.5	20-25	Expert consultation
Psychologist	22.5	20-25	Expert consultation
Psychiatrist	5.5	1–10	Expert consultation
General practitioner	5.5	1-10	Expert consultation
Durations for professionals to be involved (in hrs	s), if not involved f	or whole duration	
During ACP discussions			
Medical consultant	0.82	-	Expert consultation
Social worker	3.06	2.04-4.08	Expert consultation
Occupational therapist	3.06	2.04-4.08	Expert consultation
Speech and language therapist	3.06	2.04-4.08	Expert consultation
Psychologist	3.06	2.04-4.08	Expert consultation
Psychiatrist	3.06	2.04-4.08	Expert consultation
General practitioner	3.06	2.04-4.08	Expert consultation
Unit costs (in £)			
Care coordinator	75.6	43.2-108	PSSRU (2016), p. 14; face-to-face time Band 5/6 community nurse (£43.2 to £52.8),hospital-based (£86 to 108).
Advocate	58		PSSRU (2016), p. 58; client-related time.
Clinician	148.5	135-162	PSSRU (2016); p. 191; face-to-face time specialty doctor.
Solicitor	100		Expert consultation.
Social worker	67	55-79	PSSRU (2016), p. 156; face-to-face time social worker (adults)
Occupational therapist	48.4	44-52.8	PSSRU (2016), p. 159; unit cost multiplied with 1.2 for face-to-face time.
Speech and language therapist	48.4	44-52.8	As above

TABLE 1 (Continued)

	Mean or deterministic				
Parameter	value	Range	Source and details		
Psychologist	120.1	99.3-140.9	PSSRU (2015), p. 90; Band 8 clinical psychologist, Band 6 mental health nurse; uprated to 2016 prices.		
Psychiatrist	151.8	138-165.6	PSSRU (2016), p. 191, psychiatric consultant (hospital); multiplied with 1.2 for face-to-face time.		
General practitioner	122.5	11-134	PSSRU (2016), p. 145; GP unit cost estimate excluding direct care staff costs.		
Cost of training course (in £)	200	184-300	Expert consultation		
No. of participants	7	6-8	Expert consultation		
Length of training (in hours)	4		Expert consultation		
Parameters for estimating cost consequences link	ed to life-prolong	ing treatment: ACP	group		
Probability that ACP offered to person	81%	72.9%-89.1%	Detering et al. (2010), p. 3; range \pm 10%.		
Probability that person accepts ACP (=wishes recorded)	86%	77.4%-94.6%	Detering et al. (2010), p. 3; range \pm 10%.		
Probability that recorded wishes about CPR	82%	73.8%-90.2%	Detering et al. (2010), p. 3; range \pm 10%.		
Probability that person's CPR-related wish is DNACPR	42.4%	38.2%-46.6%	Detering et al. (2010), Table 2; $n=14$ (verbal) and $n=39$ (written), divided by $n=125$ (=total no. in ACP group); range \pm 10%.		
Probability that recorded wishes about AV	75%	67.5%-82.5%	Detering et al. (2010), p. 3; range \pm 10%.		
Probability that person's AV-related wish is No AV	31.2%	28.1%-34.3%	Detering et al. (2010), Table 2; $n=10$ (verbal) and $n=29$ (written), divided by $n=125$ (=total no. in ACP group); range \pm 10%.		
Probability that person's wishes not followed	3%	2.7%-3.3%	Detering et al. (2010), Table 3; range \pm 10%.		
Parameters for estimating cost consequences link	ed to life-prolong	ing treatment: Stan	dard care group		
Probability that person's CPR wish recorded	22%	19.8%-24.2%	NCEPOD, p. 61; range \pm 10%		
Probability that person's CPR-related wish is 'Do not attempt CPR'	38%	34.3%-41.8%	Detering et al. (2010); range \pm 10%		
Probability that person's AV wish recorded	23%	20.7%-25.3%	End of Life Care Audit (EOLCA, 2016) refers to documented discussion with person about continuing or stopping ventilation		
Probability that person's AV wish is No AV	20%	18%-22%	Detering et al. (2010); range \pm 10%		
Probability that person's wish of DNACPR not followed	9.4%	8.5%-10.36%	NCEPOD, p. 61; range \pm 10%		
Probability of person's CPR wish not followed	7%	6.3%-7.7%	Detering et al. (2010); range \pm 10%		
Probabilities of cardiac arrest and CPR in last year	r of life				
Probability of in-hospital cardiac arrest per hospital admission	0.16%	0.1%-0.5%	Nolan et al. (2007); Sandroni et al. (2007)		
No. of hospital admissions in last year of life	2.28	0.11-4.45	Bardsley et al. (2019)		
Probability that person has out-of-hospital arrest	0.524%	0.47%-0.58%	BHF (2014) p. 4: No. of out-of-hospital cardiac arrests 57,345; ONS (2016); mid-year population of older people (+65yrs) of 10,948,878.		
Probability of CPR when person had cardiac arrest and no wishes recorded	43.9%	39.5%-48.2%	BHF (2014) p. 4; refers to out-of-hospital arrest; 25,143 of 57,345 received CPR.		
Probabilities of AV (and admission to intensive ca	Probabilities of AV (and admission to intensive care unit as a result) in last year of life				
Probability of death in hospital	47%	42.3%-51.7%	ONS (2016)		
Assisted ventilation for people dying in hospital	11%	9.9%-12.1%	End of Life Care Audit (EOLCA 2016, p. 32); range \pm 10%.		
Probability that assisted ventilation takes place in intensive care unit	70.33%	63.3%-77.4%	End of Life Care Audit (EOLCA 2016, p. 33); range \pm 10%.		

TABLE 1 (Continued)

Parameter	Mean or deterministic value	Range	Source and details
Unit costs (in 2015/16, £)			
CPR without intensive care unit	2,484	848-3,572	National Schedule of Reference Costs Year 2015–16; refers to inpatient cardiac arrest.
CPR with intensive care unit	14,515	4,232-18,623	Petrie et al. (2015); Table 6 (ICU, all patients); total cost was divided by no. of people using the ICU ($n=68$) as reported on p. 5; range reflects 25th and 75th centiles; adjustments were carried out to account for London Market Force Factor of 1.2417 (p. 3), i.e. amounts reported in study were divided by this to reflect national estimate; values were uprated from 2011/12 to 2015/16 prices.
Weighted cost of CPR with and without intensive care unit	4,327	1,386-5,937	Weighted estimate of costs with and without ICU; weighting based on 12.7% probability of admission to ICU for someone with cardiac arrest (NCEPOD, p. 61; original source was Nolan et al., 2007).
Cost of ICU	14,515	4,232-18,623	Petrie et al. (2015); Table 6 (ICU, all patients); total cost was divided by no. of people using ICU ($n = 68$; p. 5); adjustments to account for London Market Force Factor of 1.2417 used in study (p. 3), i.e. amounts reported were divided by this; uprated from 2011/12 to 2015/16 prices.

mean value was taken. An average health utility weight was derived from national survey data on utility scores for depression, anxiety and mixed anxiety and depression.

2.7 | Sensitivity analyses

The impact of using different assumptions about the model parameters on the results was explored through probabilistic sensitivity analysis, which considered a distribution of values for a wide range of parameters (Table 1) rather than fixed values. In addition, we conducted one-way and two-ways sensitivity analyses for key variables that were particularly uncertain. We reduced the duration of ACP discussions by half from 4 hr to 2 hr, which is closer to estimates found in the literature of 1–2 hr (Detering et al., 2010; Nguyen et al., 2017). We reduced the duration of mental health problems experienced by carers (which we halved from 5 to 2.5 months). Finally, we increased the prevalence of mental health problems for carers in the ACP group from 0 to 15%, thus, reducing the effectiveness of ACP with regards to this outcome.

3 | FINDINGS

3.1 | Cost of delivering ACP

Experts thought that in addition to the discussions, in which various professionals talk with the person and their family carer about their preferences and wishes, the process of ACP also included: the identification of persons who could benefit from ACP (this could include the identification and appointment of a Lasting Power of Attorney where appropriate), and a mental capacity assessment in relation to

ACP, which they thought was required for between 10% and 25% of people. Experts estimated durations for each of those activities: the identification process ranged from 1 to 15 min; the mental capacity assessment ranged from 1 to 2.5 hr; the discussion about treatment preferences and wishes ranged from 10 min to 8 hr (for people in very complex situations). Experts considered evidence from other studies which reported much shorter durations of between 10 min and 2 hr (average of 1 hr). They estimated average times of 2 or 4 hr (but were unable to agree on one of the two estimates).

In terms of professionals involved in the process, experts thought that a nurse or someone on a similar salary would take the lead and be present throughout the whole process of ACP. In terms of the identification of people who would be offered ACP, experts thought that this sometimes happened in the presence of an advocate, either because it was done as part of social care needs assessment (under the Care Act 2014) or because the person was supported under the Mental Health Act. In terms of the mental capacity assessment, experts thought that this varied strongly and could include family members as well as some professionals, who might need to be contacted for specialist advice. They felt unable to provide any estimates so that it was not possible to include further costs in relation to the involvement of other professionals. In terms of the main part of ACP, that is, discussions with the person and their families or carers about their preferences and wishes, experts thought that a wide range of professionals were potentially required typically as part of an ongoing process, which could include a number of reviews. However, they were only required for some persons and for certain periods of time. For each professional, experts estimated the probability that they needed to be involved, and for how long (in ranges rather than point values). We assigned unit costs of staff time to the probabilities and durations.

The cost of training was included by calculating the cost of training per professional involved in the delivery of ACP (which included

TABLE 2 Parameters, values (ranges), sources and details for estimating cost consequences linked to place of death

Danis	Mean or deterministic	Danie	Communication (Inc.)
Parameter	value	Range	Source and details
Probabilities of dying in	different places, st	andard care group	
Hospital	47.7%	42.9%-50.6%	ONS (2016); Table 8, deaths: place of occurrence and sex by underlying cause and age group; calculated for 65yrs+.
Home	21.6%	19.4%-23.8%	As above
Care home	24.8%	22.3%-27.3%	As above
Hospice	0.5%	0.45%-0.55%	As above
Relative risk of dying in o	different settings, A	ACP versus standar	d care group
Hospital	0.46	0.42-0.51	Dixon et al. (2019), p. 8; range \pm 10%.
Home (rather than hospital)	2.93	2.90-2.94	Dixon et al. (2019); derived from odds ratio (and range) with conversion formula: $RR = OR/(1 - p_0 + p_0 \times OR).$
Care home (rather than hospital)	1.68	1.63-1.71	Dixon et al. (2019); derived from odds ratio (and range) with conversion formula: $RR = OR/(1 - p_0 + p_0 \times OR).$
Hospice	1.52	0.76-1.52	Detering et al. (2010).
Probabilities of dying in	different settings,	ACP group	
Hospital	21.9%	17.8%-26.5%	Derived from parameters above: probability of dying in hospital in standard care multiplied by relative risk of dying in hospital, ACP versus standard care.
Home (rather than hospital)	63.3%	56.5%-70.1%	Derived from parameters above: probability of dying at home in standard care multiplied by relative risk of dying at home, ACP versus standard care.
Care home (rather than hospital)	47.1%	40.1%-54%	Derived from parameters above: probability of dying in hospital in standard care multiplied by relative risk of dying in hospital, ACP versus standard care.
Hospice	0.77%	0.34%-0.84%	Derived from parameters above: probability of dying in hospital in standard care multiplied by relative risk of dying in hospital, ACP versus standard care.
Unit costs (in £ 2015/16))		
Death at home	1,862	1,021-2,661	Own calculation; see Appendix SA3.
Death in hospital	3,000	2,506-3,779	Refers to average cost of inpatient admission that ends in death; Mean is tariff suggested by QIPP programme (NEOLCP 2012); lower estimate is from NICE (2011); higher estimate from Georghiou and Bardsley (2014).
Death in care home	1,192	831-1,554	PSSRU (2016), p. 205; Refers to cost of residential care or nursing home for people 65 years +; for 12.9 days.
Death in hospice	5,121	3,728-6,966	PSSRU (2016); refers to inpatient specialist palliative care for adults per day; multiplied by 12.9 days.

the fee for the training course and the time spent by professionals for attending the training), and then allocating them based on probability that the person needed to be present at the meeting and an assumption that the training lasted 50 deliveries before a refresher was required.

The average cost per person was £87 for identifying the person, £23.15 for assessing mental capacity (if needed) and £694 for ACP discussions. The total mean cost of ACP – including the cost of training – was £821. Upper and lower values were £214 and £1,874 and reflected different estimates on resource inputs.

3.2 | Incremental cost consequences

Mean costs per person linked to the use of cardiopulmonary resuscitation in the ACP versus standard care group were £38 with

a standard deviation (*SD*) of 33 and a 95% confidence interval (CI) of 36–40 versus £40 (*SD* 34, 95% CI 38–42). For assisted ventilation, costs were £448 (*SD* 225, 95% CI 435–461) versus £516 (*SD* 222, 95% CI 503–529). Mean costs linked to differences in place of death in the ACP versus standard care group were £2,416 (*SD* 251, 95% CI 2,408–2,439) versus £2,517 (*SD* 260, 95% CI 2,501–2,533).

3.3 | Total incremental costs

Total mean costs per person in the ACP versus standard care group over 1 year were £3,739 (SD 529, 95% CI 3,706–3,772) versus £3,069 (SD 375, 95% CI 3,046–3,092). The mean difference in total costs between the two groups was £670 (SD 426, 95% CI 644–697).

TABLE 3 Parameters, values (ranges), sources and details for estimating carers' health-related quality of life

	Mean or deterministic		
Parameter	value	Range	Source and details
Probability of anxiety or depression, ACP group	0	SA: 0.15	Detering et al. (2010)
Probability of anxiety or depression, standard care	0.4	0.3-0.49	Detering et al. (2010); minimum value refers to probability of depression if 100% overlap with anxiety problems was assumed; maximum value refers to probability of either depression or anxiety if 0% overlap between the 2 conditions was assumed; mean is midpoint between minimum and maximum values.
Duration of mental health problems (in years)	0.42	0.33-0.5	Assumptions; maximum time was informed by Detering et al. (2010), which had a follow up of 6 months.
Health utilities			
Depression	0.537	SD 0.311	Roberts et al. (2014); refers to representative sample of the general adult population in England; health utilities measured with the EQ-5D were taken for the model.
Anxiety	0.643	SD 0.288	As above
Mixed anxiety and depression	0.681	SD 0.258	As above
Weighted health utility: anxiety: depression; anxiety and depression combined	0.62	0.35-0.91	Mean calculated from above health utilities; presents an average across health utilities for: depression; anxiety; depression and anxiety combined.
No mental health problems	0.827	SD 0.114	Roberts et al. (2014); refers to representative sample of the general adult population in England.

Note: SA, Sensitivity analysis; SD, Standard deviation.

3.4 | Incremental effects

All parameters, value (ranges) and data sources used for the modelling of carers' health-related quality-of-life are shown in Table 3.

The mean carer's health-related quality-of-life over the 1 year was 0.83 in the ACP group (SD 0.07, 95% CI 0.83–0.84) and 0.80 in the standard care group (SD 0.06, 95% CI 0.79–0.80). The QALY gain in the ACP compared with the standard care group was 0.03 (SD 0.02, 95% CI 0.03–0.04).

3.5 | Incremental cost-effectiveness ratio

The ICER – calculated by dividing total incremental costs with incremental effects – was £18,966 per (QALY) gained. Graphs 3 and 4 illustrate the base case findings in the form of a cost-effectiveness plane (Graph 3) and curve (Graph 4), which demonstrate the uncertainty of the ICER. In more than 55% of altogether 1,000 Monte Carlo simulation runs, ACP was more cost-effective than standard care at a cost per QALY threshold of £20,000. At a higher threshold of £30,000 per QALY, the probability that ACP was cost-effective was 70%.

3.6 | Sensitivity analyses

Results of additional one- and two ways sensitivity analyses can be found in Appendix SA2 (Graphs S1–S3). The probability of

cost-effectiveness increased from 55% to 90% at a cost per QALY threshold of £20,000, if the average length of ACP was 2 hr or less rather than 4 hr (Graph S1). The probability that ACP was cost-effective reduced to 30% at a cost per QALY threshold of £20,000 when the duration over which carers experienced mental health problems was halved (Graph S2), and to under 10% when the prevalence of mental health problems in the ACP group was increased to 15 per cent (Graph S3). However, two-ways analyses (Graph S4) showed that the average duration of ACP was the single most important parameter with the strongest influence on whether or not ACP was likely to be cost-effective. They showed that the probability that ACP was cost-effective remained as high as 60% or 70% when the duration of ACP discussions were 2 hr even when the prevalence of mental health problems in the ACP group was 15% (Graph S4).

4 | DISCUSSION

4.1 | Main findings

To our knowledge, this is the first economic study, which explores the cost-effectiveness of a strategy, in which ACP is offered systematically for the general population of older people reaching end-of-life. This was explored from a carer perspective, that is, outcomes considered referred to mental health improvements of carers. Our findings suggest that a strategy in which ACP is provided following good practice in England has a probability of 55% (70%) of being

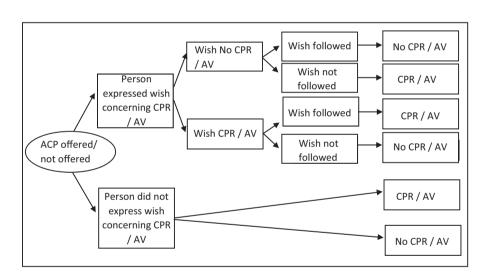
Box 1 Overview of consultation with experts for estimating resource input for the delivery of advance care planning

The cost of delivering advance care planning for older people in their last year of life was assessed in an iterative process in close collaboration with a *subgroup of the guideline committee*. The guideline committee was responsible for developing the national guideline, and met for this purpose at regular intervals every month or so over the period of one and a half year.

The committee consisted of 16 and the subgroup of 6 members (all of whom were experts in matters concerning advance care planning and mental capacity assessment). Discussions and final agreements took place with all members of committee (12 members), whom were informed about the work of the subgroup and were asked to sign off the decisions made by the subgroup.

Based on initial consultation with the guideline committee, good practice guidelines and the literature, the researchers developed a semi-structured questionnaire, which covered questions about: the process of delivering ACP, professionals involved and their required training.

The process of gathering responses to the questionnaire was iterative: First, the questionnaire was sent to members of the subgroup (per email). Based on their responses, we sought clarification on issues of disagreement between responses, and asked additional questions where we needed more detailed information, such as: the duration of the process; the time each professional spent on the process; training requirements. In particular, we asked members of the subgroup to specify the average, minimum and maximum time each professional spent on the process; this also included questions about the estimated probabilities that involvement of different professionals was required. Where it was not possible to reach consensus (which was the case in particular for the length of ACP discussions), we agreed with the committee to test implications of changes in values of these parameters on findings in additional sensitivity analysis.



GRAPH 1 Model for evaluating cost consequences of advance care planning (ACP) linked to life-prolonging treatment. Explanation: People in the two groups (ACP and standard care) could either express a wish concerning CPR (AV), or not express such wish. The wish could be to receive CPR (AV) or to not receive such treatment. This wish could then either be followed or not followed, and as a result they either received or did not receive CPR (AV)

cost-effective when compared with standard care at a cost per QALY threshold of £20,000 (£30,000). Our findings are highly sensitive to the duration of ACP (which was substantially longer in our study because experts estimated the costs of ACP as an ongoing, personalised and multidisciplinary process), and to the effectiveness of ACP in terms of carer's quality-of-life. Model structure and parameters were done in comprehensive consultation with recognised experts in the field. This ensured that the model was relevant to current practice. In addition, by carefully evaluating the resource inputs and costs of ACP, this study addressed an important gap in the evidence (Abel et al., 2013; Detering et al., 2010; Dixon et al., 2019; Dixon & Knapp, 2019; Klingler et al., 2016; Nguyen et al., 2017; Rietjens et al., 2017).

4.2 | Limitations

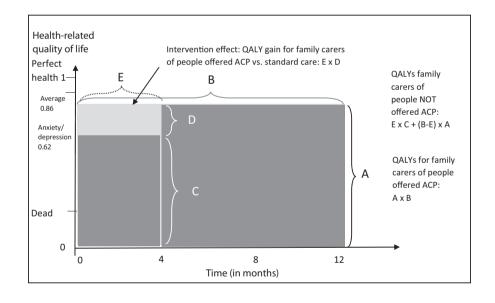
This study had several limitations. For example, there are other life-prolonging treatments (such as chemotherapy) that potentially reduce when ACP is introduced (Wright et al., 2008; Zhang et al., 2009) but which were not included either because they referred to a particular group (e.g. people with cancer) or because there was insufficient data to include them (e.g. assisted nutrition), or both. Similarly, there was no evidence on the impact of ACP on the time spent caring, and so this study did not consider this cost to individuals. The study considered only mental health outcomes to family carers, and did not include benefits for people dying or for other beneficiaries such as healthcare organisations or health and

Box 2 Calculations for deriving probabilities in Adjustment to odds ratios from Dixon et al. (2019) to derive probabilities for dying in different settings (home, care home and hospital) in advance care planning group

Dixon et al. (2019) provides odds ratios that compared effects of advance care planning on place of death by looking at two places of death in relation to each other, i.e. death in hospital versus death at home and death in hospital versus death in a care home (rather than death at home or a care home versus death elsewhere). For the analysis, 4 different places of death were considered as outcomes affected by advance care planning: Death in hospital, death at home, death in a care home and death in a hospice. In order to derive probabilities for the four places of death, the following calculations were carried out:

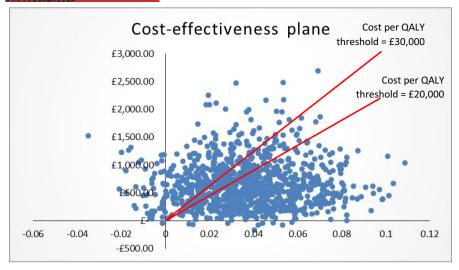
- 1. Probabilities for dying in the four different settings in standard care (p0) were estimated based on national statistics.
- 2. Probabilities for dying in these different settings in the advance care planning group (p1) were then derived based on probabilities in standard care and relative risk (RR) data using the formula: p1 = p0*RR.
- 3. The relative risks (RR) for dying in hospital, at home and in a care home in the advance care planning group compared with standard care were either directly available from Dixon et al. (2019) or Detering et al. (2010) or were calculated from odds ratios (OR) using the following formula RR = OR/ $(1 p0 + p0 \times OR)$.
- 4. Next, adjusted probabilities (pAdj) for dying in a care home and at home were calculated to ensure that probabilities of dying in the four settings added up to 100%. This step was required to account for the fact that relative risks derived from Dixon et al. (2019) referred to relative effects of dying in care home or at home (versus dying in hospital).
 - a. The probability for a person NOT to die either in a hospital or in a hospice was calculated based on the above probability data. The resulting probability was assumed to be residual probability for a person to die either at home OR in a care home (pResidual).
 - b. Adjusted probabilities were calculated for a person to die at home and for a person to die in a care home as follows: pAdj (death at home) = pResidual * ((p (death at home)/ (p (death at home) + p (death in care home)) pAdj (death in care home) = pResidual * p (death in care home)/ (p (death at home) + p(death in care home))

GRAPH 2 Calculations of qualityadjusted life year (QALY) gain due to differences in depression and anxiety experienced by family carers of people offered versus those NOT offered advance care planning (ACP)

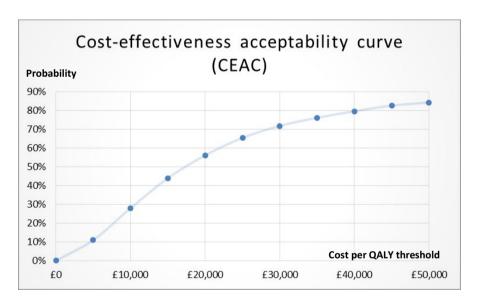


care staff, which are much harder to evidence or quantify (Dixon et al., 2015; Zhang et al., 2009). Mental health outcomes were translated into QALYs by applying health utility weights to states of depression and anxiety. While this is a commonly used method for considering mental health symptoms into economic evaluations, it does not take into account wider health or well-being benefits. Furthermore, it is possible that our consultation with experts led to a high estimate of the resources required for ACP (Dixon & Knapp, 2018). In addition, not all estimates refer to the specific

population and are instead values for the general adult population. Although this study sought to reflect a variety of practice of ACP as applied to different populations, findings from this study might not be generalisable to specific populations such as people with cancer or people with dementia. For people with cancer, cost saving is potentially greater than those estimated here, since we did not consider the use of chemotherapy, for which there is evidence from the US that this can be lower for people who had ACP (Wright et al., 2008; Zhang et al., 2009). However, how this applies



GRAPH 3 Cost-effectiveness plane of base case results. Explanation: The cost-effectiveness plane shows the different possible combinations of incremental costs and incremental effects; all dots on or under the lines present cost-effective combinations of incremental costs and effects. Here, only at a willingness-to-pay threshold of £30,000 per QALY, more dots lie under than above the line, thus, signalling that ACP is cost-effective only at that higher threshold [Colour figure can be viewed at wileyonlinelibrary.com]



GRAPH 4 Cost-effectiveness acceptability curve of base case results. Explanation: The cost-effectiveness acceptability curve plots a range of cost-effectiveness thresholds on the horizontal axis against the probability that advance care planning is cost-effective at each of these thresholds on the vertical axis

to England has to our knowledge not yet been investigated. For people with dementia, findings on costs and effects might be very different from those estimated here depending on when ACP is provided and in which setting. There is increasing consensus that ACP needs to be provided at an early stage before the dementia progresses, which – for some – might be as early as shortly after the initial diagnosis (Dening, Jones, & Sampson, 2011; Nguyen et al., 2017; Poppe, Burleigh, & Banerjee, 2013). The impact on family carers' mental health might be very different at this earlier stage. In addition, research studies would need longer follow-up periods to capture relevant costs and benefits.

4.3 | Interpretation of findings

Our modelling only included a limited set of possible outcomes and cost consequences. In particular, it only considered health outcomes to family carers. However, by only including a limited set of benefits (viz. to family carers) and even before considering other potential benefits, ACP was likely to be cost-effective. As long as it can be assumed that it does not cause harms or costs elsewhere, findings suggest that rolling out would probably be cost-effective.

However, there are some possible reasons why ACP if implemented in actual practice might not achieve economic gains. While

there is an increasing agreement about how ACP should be delivered (Rietjens et al., 2017), there is substantial variation in current practice, which impacts on the costs, acceptability and effectiveness of ACP, and hinders generalisable conclusions about its (economic) impact (Dixon & Knapp, 2019; Klingler et al., 2016). Previous studies (Detering et al., 2010; Nguyen et al., 2017) did not consider the costs of involving other professionals in ACP (such as doctors or occupational therapists), which was an important cost component in our study. More research is needed to understand the costs of good practice ACP (Korfage et al., 2015). This might need to include the cost of implementing ACP, which is likely to require substantial resources linked to training, awareness raising and information sharing (Chung, Wong, Oh, & Ho, 2013; Lovell & Yates, 2014; Lund, Richardson, & May, 2015; Schofield et al., 2015).

Possibly reflecting a perceived policy priority on cost savings (Billings, 2012; Klingler et al., 2016) previous economic studies focused on evaluating costs rather than cost-effectiveness (Dixon et al., 2019; Klingler et al., 2016). This includes a modelling study (Nguyen et al., 2017) which – although formally a cost-effectiveness analysis – assumed zero changes in health outcomes and only looked at changes in costs. Leaders of healthcare organisations providing system-wide ACP are much more concerned about realising the economic value of ACP than cost savings (Dixon & Knapp, 2019). This included benefits to carers and staff. Future (cost-) effectiveness studies should investigate the various benefits to different groups of beneficiaries (Biondo, Lee, Davison, & Simon, 2016; Jimenez et al., 2018; Korfage et al., 2015; Robinson et al., 2011).

5 | CONCLUSIONS

Conducting cost-effectiveness analysis for ACP is challenging due to uncertainties in practice and research, such as a lack of agreement how ACP should be provided (which influences its costs), and about relevant beneficiary groups (which influences its outcomes). However, even when assuming relatively high costs for ACP delivery and only one beneficiary group, our analysis showed that ACP in our analysis was cost-effective.

ACKNOWLEDGEMENTS

This work was produced for and funded by the National Institute for Health and Care Excellence for the 'Decision making and mental capacity' guideline [NG108]. We are grateful to the support we received from individuals employed by Social Care Institute for Excellence and by the National Institute for Health and Care Excellence, who – as part of the development of the guideline to which this work contributed – provided important research expertise and inputs as well as managerial and administrative leadership and support. In particular, we are grateful for the guidance, advice and support we received from Beth Anderson, Jennifer Francis, Hannah Roscoe, Zenette Abrahams, Palida Teelucknavan, Ted Baker, Leslie Hayes and Nick Staples. This study was importantly informed by the following experts with professional or lived experience, many of

whom gave much of their time and goodwill to this work: Eve Baird, Lucy Nooerjea, Julie Carr, Antoinette Foers, Nageena Khalique, Phil Ruthen, James Shutt, Anna Volkmer and Robert Walker.

CONFLICTS OF INTEREST

All authors (Annette Bauer, Josie Dixon, Martin Knapp and Raphael Wittenberg) declare that they do not have any conflicts of interest.

ORCID

Annette Bauer https://orcid.org/0000-0001-5156-1631

Josie Dixon https://orcid.org/0000-0003-4772-6450

Martin Knapp https://orcid.org/0000-0003-1427-0215

Raphael Wittenberg https://orcid.org/0000-0003-3096-2721

REFERENCES

- Abel, J., Pring, A., Rich, A., Malik, T., & Verne, J. (2013). The impact of advance care planning of place of death, a hospice retrospective cohort study. BMJ Supportive & Palliative Care, 3(2), 168–173. https:// doi.org/10.1136/bmjspcare-2012-000327
- Albers, G., Echteld, M. A., de Vet, H. C., Onwuteaka-Philipsen, B. D., van der Linden, M. H., & Deliens, L. (2010). Evaluation of quality-of-life measures for use in palliative care: A systematic review. *Palliative Medicine*, 24(1), 17–37. https://doi.org/10.1177/0269216309346593
- Bardsley, M., Georghiou, T., Spence, R., & Billings, J. (2019). Factors associated with variation in hospital use at the end of life in England. *BMJ Supportive & Palliative Care*, 9(2), 167–174. https://doi.org/10.1136/bmjspcare-2015-000936
- Beckett, A., Leary, K., Cumming, L., & Davies, G. (2014). The Future of Lasting Power of Attorney. London: Office of the Public Guardian, Ipsos MORI. Available from: https://www.gov.uk/government/uploa ds/system/uploads/attachment_data/file/358560/OPG_LPA_Ipsos -MORI_Nov_13.pdf [last accessed 04 August 2020].
- BHF. (2014). Consensus paper on out-of-hospital cardiac arrest in England. London: British Heart Foundation.
- Billings, J. A. (2012). The need for safeguards in advance care planning. *Journal of General Internal Medicine*, 27(5), 595–600. https://doi.org/10.1007/s11606-011-1976-2
- Biondo, P. D., Lee, L. D., Davison, S. N., & Simon, J. E. (2016). How health-care systems evaluate their advance care planning initiatives: Results from a systematic review. *Palliative Medicine*, 30(8), 720–729. https://doi.org/10.1177/0269216316630883
- Bischoff, K. E., Sudore, R., Miao, Y., Boscardin, W. J., & Smith, A. K. (2013). Advance care planning and the quality of end-of-life care in older adults. *Journal of the American Geriatrics Society*, 61(2), 209–214. https://doi.org/10.1111/jgs.12105
- Brinkman-Stoppelenburg, A., Rietjens, J. A., & van der Heide, A. (2014). The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*, 28(8), 1000–1025. https://doi.org/10.1177/0269216314526272
- Carr, D., & Luth, E. A. (2017). Advance care planning: Contemporary issues and future directions. *Innovation in Aging*, 1(1), igx012. https://doi.org/10.1093/geroni/igx012
- Chung, I., Wong, C., Oh, C., & Ho, S. Y. (2013). Implementing a national advance care planning (ACP) programme in Singapore. *BMJ Supportive & Palliative Care*, 3(2), 256–257. https://doi.org/10.1136/bmjspcare-2013-000491.82
- Curtis, L., & Burns, A. (2016). Unit costs of health & social care 2016. Retrieved from Kent.
- Dening, K. H., Jones, L., & Sampson, E. L. (2011). Advance care planning for people with dementia: A review. *International Psychogeriatrics*, 23(10), 1535–1551. https://doi.org/10.1017/s1041610211001608

- Department of Health. (2015). End of life care strategy: Promoting high quality care for adults at the end of their life. London: Department of. Health and Social Care. Retrieved from https://www.gov.uk/government/publications/end-of-life-carestrategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life.
- Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *BMJ*, 340, c1345. https://doi.org/10.1136/bmj.c1345
- DHSC. (2016). NHS reference costs 2015 to 2016. London: Department of Health and Social Care.
- Dixon, J., King, D., & Knapp, M. (2019). Advance care planning in England: Is there an association with place of death? Secondary analysis of data from the National Survey of Bereaved People. BMJ Supportive & Palliative Care, 9, 316–332. https://doi.org/10.1136/bmjsp care-2015-000971
- Dixon, J., King, D., Matosevic, T., Clark, M., & Knapp, M. (2015). Equity in the provision of palliative care in the UK: review of evidence. London.
- Dixon, J., & Knapp, M. (2018). Whose job? The staffing of advance care planning support in twelve international healthcare organizations: A qualitative interview study. *BMC Palliative Care*, 17(1), 78. https://doi.org/10.1186/s12904-018-0333-1
- Dixon, J., & Knapp, M. (2019). Delivering advance care planning support at scale: A qualitative interview study in twelve international healthcare organizations. *Journal of Long-term Care*, 2019, 127–142. http:// doi.org/10.31389/jltc.7
- Dixon, J., Matosevic, T., & Knapp, M. (2015). The economic evidence for advance care planning: Systematic review of evidence. *Palliative Medicine*, 29(10), 869–884. https://doi.org/10.1177/0269216315 586659
- Georghiou, T., & Bardsley, M. (2014). Exploring the cost of care at the end of life. Retrieved from London.
- Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. J. (2013). Heterogeneity and changes in preferences for dying at home: A systematic review. BMC Palliative Care, 12(1), 7. https://doi. org/10.1186/1472-684X-12-7
- Jimenez, G., Tan, W. S., Virk, A. K., Low, C. K., Car, J., & Ho, A. H. Y. (2018). Overview of systematic reviews of advance care planning: Summary of evidence and global lessons. *Journal of Pain and Symptom Management*, 56(3), 436–459.e425. https://doi.org/10.1016/j.jpain symman.2018.05.016
- Jutte, J. E., Needham, D. M., Pfoh, E. R., & Bienvenu, O. J. (2015).
 Psychometric evaluation of the Hospital Anxiety and Depression Scale 3 months after acute lung injury. *Journal of Critical Care*, 30(4), 793–798. https://doi.org/10.1016/j.jcrc.2015.04.006
- Klingler, C., in der Schmitten, J., & Marckmann, G. (2016). Does facilitated Advance Care Planning reduce the costs of care near the end of life? Systematic review and ethical considerations. *Palliative Medicine*, 30(5), 423–433. https://doi.org/10.1177/0269216315 601346
- Korfage, I. J., Rietjens, J. A. C., Overbeek, A., Jabbarian, L. J., Billekens, P., Hammes, B. J., ... van der Heide, A. (2015). A cluster randomized controlled trial on the effects and costs of advance care planning in elderly care: Study protocol. *BMC Geriatrics*, 15, 87. https://doi.org/10.1186/s12877-015-0087-z
- Lovell, A., & Yates, P. (2014). Advance Care Planning in palliative care: A systematic literature review of the contextual factors influencing its uptake 2008–2012. *Palliative Medicine*, 28(8), 1026–1035. https://doi.org/10.1177/0269216314531313
- Lund, S., Richardson, A., & May, C. (2015). Barriers to advance care planning at the end of life: An explanatory systematic review of implementation studies. *PLoS One*, 10(2), e0116629. https://doi. org/10.1371/journal.pone.0116629
- MarieCurie. (2012). Understanding the cost of end of life care in different settings. London: Marie Curie Cancer Care.

- Mullick, A., Martin, J., & Sallnow, L. (2013). An introduction to advance care planning in practice. BMJ, 347, f6064. https://doi.org/10.1136/ bmj.f6064
- NCEPOD. (2012). Time to intervene? A review of patients who underwent cardiopulmonary resuscitation as a result of an in-hospital cardiorespiratory arrest. Retrieved from London.
- Nguyen, K. H., Sellars, M., Agar, M., Kurrle, S., Kelly, A., & Comans, T. (2017). An economic model of advance care planning in Australia: A cost-effective way to respect patient choice. *BMC Health Services Research*, 17(1), 797. https://doi.org/10.1186/s12913-017-2748-4
- NICE. (2009). Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (Review of TA 111). Final scope. National Institute for Health and Care Excellence. Retrieved from https://www.nice.org.uk/guidance/ta217/documents/alzheimers-disease-mild-to-moderate-donepezil-galantamine-rivastigmine-and-memantine-part-review-final-scope2
- NICE. (2011a). End of life care for adults. Quality standard [QS13]. National Institute for Health and Care Excellence. Retrieved from https://www.nice.org.uk/guidance/qs13
- NICE. (2011b). Service user experience in adult mental health services, Quality statement 9: Crisis planning. Retrieved from London.
- NICE. (2017). Decision making and mental capacity; Appendix C3: Economic report. Retrieved from London.
- NICE. (2018). Decision-making and mental capacity. NICE guideline [NG108]. Retrieved from London.
- Nicholas, L. H., Bynum, J. P., Iwashyna, T. J., Weir, D. R., & Langa, K. M. (2014). Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health Affairs*, 33(4), 667–674. https://doi.org/10.1377/hltha ff.2013.1258
- Nolan, J. P., Laver, S. R., Welch, C. A., Harrison, D. A., Gupta, V., & Rowan, K. (2007). Outcome following admission to UK intensive care units after cardiac arrest: A secondary analysis of the ICNARC Case Mix Programme Database. *Anaesth*, 62(12), 1207–1216. https://doi.org/10.1111/j.1365-2044.2007.05232.x
- ONS. (2016). Deaths registered in England and Wales (series DR), Deaths by place of occurence, 2016. Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/007620deathsbyplaceofoccurrence2016
- Petrie, J., Easton, S., Naik, V., Lockie, C., Brett, S. J., & Stümpfle, R. (2015). Hospital costs of out-of-hospital cardiac arrest patients treated in intensive care; a single centre evaluation using the national tariff-based system. *British Medical Journal Open*, 5(4), e005797. https://doi.org/10.1136/bmjopen-2014-005797
- Poppe, M., Burleigh, S., & Banerjee, S. (2013). Qualitative evaluation of advanced care planning in early dementia (ACP-ED). *PLoS One*, 8(4), e60412. https://doi.org/10.1371/journal.pone.0060412
- PSSRU (2015). Unit Costs of Health and Social Care 2015, Personal Social Services Research Unit, Canterbury: University of Kent.
- PSSRU (2016). Unit Costs of Health and Social Care 2016, Personal Social Services Research Unit. Canterbury: University of Kent.
- RCP. (2016). End of life care audit Dying in hospital: National report for England 2016. London: Royal College of Physicians. Available from: https://www.hqip.org.uk/resource/end-life-care-audit-dying-hospital-final-report-2016/ [last accessed: 04 August 2020].
- Rietjens, J. A. C., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., ... Korfage, I. J. (2017). Definition and recommendations for advance care planning: An international consensus supported by the European Association for Palliative Care. *Lancet Oncology*, 18(9), e543-e551. https://doi.org/10.1016/S1470-2045(17)30582-X
- Roberts, J., Lenton, P., Keetharuth, A. D., & Brazier, J. (2014). Quality of life impact of mental health conditions in England: Results from the adult psychiatric morbidity surveys. *Health and Quality of Life Outcomes*, 12, 6. https://doi.org/10.1186/1477-7525-12-6

- Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., ... Exley, C. (2011). A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing*, 41(2), 263–269. https://doi.org/10.1093/ageing/afr148
- Sandroni, C., Nolan, J., Cavallaro, F., & Antonelli, M. (2007). In-hospital cardiac arrest: Incidence, prognosis and possible measures to improve survival. *Intensive Care Medicine*, 33(2), 237–245. https://doi.org/10.1007/s00134-006-0326-z
- Schofield, G., Kreeger, L., Meyer, M., Swann, D., Wijeratne, A., Wood, J., & Stone, P. (2015). Implementation of a quality improvement programme to support advance care planning in five hospitals across a health region. *BMJ Supportive & Palliative Care*, 5(1), 91–94. https://doi.org/10.1136/bmjspcare-2013-000574
- Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., ... Prigerson, H. G. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA, 300(14), 1665–1673. https://doi.org/10.1001/jama.300.14.1665
- Zhang, B., Wright, A. A., Huskamp, H. A., Nilsson, M. E., Maciejewski, M. L., Earle, C. C., ... Prigerson, H. G. (2009). Health care costs in the last week of life: Associations with end of life conversations. *Archives*

- of Internal Medicine, 169(5), 480–488. https://doi.org/10.1001/archinternmed.2008.587
- Zwakman, M., Jabbarian, L. J., van Delden, J., van der Heide, A., Korfage, I. J., Pollock, K., ... Kars, M. C. (2018). Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness. *Palliative Medicine*, 32(8), 1305–1321. https://doi.org/10.1177/0269216318784474

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Bauer A, Dixon J, Knapp M, Wittenberg R. Exploring the cost-effectiveness of advance care planning (by taking a family carer perspective): Findings of an economic modelling study. *Health Soc Care Community*. 2021;29:967–981. https://doi.org/10.1111/hsc.13131