

DECISION-MAKING AND MENTAL CAPACITY

Appendix C3: Economic report

This report was produced by the Personal Social Services Research Unit at the London School of Economics and Political Science. PSSRU (LSE) is an independent research unit and is contracted as a partner of the NICE Collaborating Centre for Social Care (NCCSC) to carry out the economic reviews of evidence and analyses.

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2 1 Background and rationale for economic work

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4 The aim of the economic work was to contribute to the development of the guideline
5 'Decision-Making and Mental Capacity' by providing evidence on the cost-effectiveness for 1
6 or several areas covered by this guideline. Areas were chosen based on the expected
7 economic impact, the expected contribution from doing additional economic work, and
8 feasibility of doing this work. All 3 criteria were strongly influenced by the availability of
9 published evidence. This and the following sections provide a summary of the economic
10 evidence that was identified as part of the systematic review (details on how the systematic
11 review was carried out can be found in Appendix A), and how this led to the prioritisation of
12 the economic work on advance care planning.

13 Economic studies were identified only for review question 1 on 'Planning in advance,
14 including for people who experience fluctuating capacity'. The economic studies responded
15 to review question 1.1: 'What interventions, tools, aids and approaches are effective and
16 cost-effective in supporting advance planning for decision-making for people who may lack
17 mental capacity in the future?'

18 Economic studies that responded to this review question referred to 2 areas of interventions:
19 Advance care planning (ACP) towards end of life and Joint crisis planning (JCP) for people
20 with severe mental health problems. Advance care planning has been defined as 'the
21 process of discussing and recording patient preferences concerning goals of care for
22 patients who may lose capacity or communication ability in the future' (Brinkman-
23 Stoppelenburg et al. 2014, adapted from Seymour et al. 2010). ACP is concerned with the
24 wishes and preferences people might have towards the end of life, in particular regarding
25 treatment and place of death. ACP can include the completion of written documents
26 including: legally binding advance directives (including living wills); the appointment of a
27 Lasting Power of Attorney (LPA), who can make decisions if the person loses their capacity;
28 advance statements (for particular preferences); and advance decisions (to refuse particular
29 treatments; this includes Do Not Attempt Cardio Pulmonary Resuscitation DNACPR).

30 Joint Crisis Planning (JCP) is another process of shared decision-making, in which a person
31 with severe mental health problems can make advance statements and decisions. The
32 intervention is usually targeted at people who are in contact with mental health services. It
33 refers to a process in which a person at risk of losing mental capacity during a mental health
34 crisis develops a plan together with mental health professionals. This plan sets out the
35 treatment they want to get in any future emergency situation, when the person might be too
36 unwell to express their wishes coherently (Henderson et al. 2004). NICE (2011) guidance
37 sets out that a JCP should contain the following elements: possible early warning signs of a
38 crisis and coping strategies; support available to help prevent hospitalisation; where the
39 person would like to be admitted in the event of hospitalisation; the practical needs of the
40 service user if they are admitted to hospital (for example, childcare or the care of other
41 dependants, including pets); details of advance statements and advance decisions; whether
42 and the degree to which families or carers are involved; information about 24-hour access to
43 services; named contacts.

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2 Summary of economic evidence

2.1 Advance care planning (ACP)

Two systematic reviews of economic evidence and 1 single economic study from England (UK) were identified.

One systematic review of economic evidence on ACP carried out in the UK (Dixon et al. 2015, ++) identified 18 studies published between 1990 and 2014 from US, UK, Canada, Singapore. Studies were included if they reported economic outcomes in relation to ACP and in which ACP was a standalone intervention or formed an important component of a wider palliative care or support programme. While the authors did not define economic outcomes, it was clear from their reporting of study details that this referred to costs (and cost-effectiveness results, although no study was identified which measured this). Studies were excluded if they were solely about medical orders or advance directives in relation to power of attorney and if they were targeting psychiatric patients or children. Of the total 18 studies that were identified, 5 used a randomised design, 10 used natural experiments and 3 non-randomised designs. Sample sizes ranged from 50 to more than 3000. Seven studies focused on hospital-based samples; 3 studies were from nationally representative data from the US Health and Retirement Study of older people.

The review found no published cost-effectiveness studies. Included economic studies were cost savings ones. Different types of costs were evaluated using different methods and data sources but the focus was on costs of hospital care. Eleven studies reported positive results regarding cost savings, largely due to reductions in hospital admissions or in the use of intensive care. However, most studies followed a narrow health cost perspective and primarily included the costs of hospital care. Some studies included costs of other health and social care such as nursing home and particular forms of community healthcare (such as polyclinics in Singapore). Cost savings ranged from US Dollar (USD) 64,827 for the terminal hospital stay to USD 56,700 for total healthcare costs over the past 6 months for people with dementia and USD 1,041 in hospital costs over the last week of life for those with cancer. While the systematic review found that most studies did not provide sufficient detail that would have allowed analyses of the source of cost savings, the majority reported reductions in a range of service outcomes that were likely to explain some of the cost savings. This included reductions in: hospital deaths; intensive care unit (ICU) admissions; life-prolonging treatments; hospitalisations; length of hospital stay. In addition, the systematic review highlighted the following issues of economic studies on ACP: Of the 18 identified studies, 8 were not evaluations of ACP but retrospective single cohort studies, which used secondary data to measure an association between ACP and costs. Another issue was the definition of ACP and how it was measured; this ranged from evidence of documented medical decisions to counselling and support services led by nurses or social workers and more complex palliative care interventions, of which ACP was only a component. Dixon et al. (2015) identified a particular challenge in interpreting findings from studies, which analysed secondary data as they provided limited data on the process of ACP and the factors known to influence the quality and effectiveness of ACP such as when and how ACP was first initiated, the professionals involved in ACP and the frequency of reviews.

The second systematic review (Klingler et al. 2016 +) – carried out in Germany – included economic evaluations published between 1994 and 2010 and identified 7 studies including 4 RCTs, 1 before and after study and 2 cohort studies. All studies were from the US and

1 Canada. Sample sizes of studies ranged from 43 to over 3,000. The authors stated that the
2 review included interventions, which contained a communication process facilitated by a
3 professional caregiver involving the patient or legal proxy about the patient's preferences for
4 future medical care. This could include interventions, in which ACP was part of a more
5 comprehensive programme to improve end-of-life care. Populations in studies were often
6 defined by their medical conditions, which included cancer, heart failure, diabetes, chronic
7 obstructive pulmonary disease. Studies collected different types of costs with a focus on cost
8 of hospice and hospital care. The authors concluded that the limited data suggested that
9 ACP could realise net cost savings. The review found significant cost reductions ($p < 0.05$) in
10 3 studies; 2 studies did not report significance and 1 study found a non-significant reduction.
11 Cost savings per patient ranged from USD 1,041 to USD 64,827. Relative cost reductions
12 ranged from 5% to 68%. Only 3 studies reported the costs of implementing ACP and those
13 ranged widely: Canadian Dollar (CAD) 113; USD 452; and USD 1,968. Other effects
14 reported included improved patient satisfaction in 2 studies; 1 study found no significant
15 effect on patient or family satisfaction. Most individual studies measured hospital costs but
16 did not include a comprehensive cost perspective; cost savings ranged from USD 1,041 to
17 USD 64,830. Studies evaluating programme costs showed that those were relatively small
18 amounting to 6 to 15% of cost savings. The authors discuss their findings in the context of
19 previously published findings from studies that investigated advance directives (ADs) –
20 defined as presence of signed legal documents – and which did not find cost reductions.
21 They concluded that this might suggest that ACP is more likely to lead to cost savings if it is
22 implemented comprehensively because it increased compliance with end-of-life wishes.
23 Similar to Dixon et al. (2015), this systematic review of economic studies concluded that cost
24 savings were explained by reductions in life-prolonging treatments and reductions in
25 hospitalisations. However, they also reported that there was an increased use of hospice
26 and palliative care in some studies.

27 In addition to the 2 systematic reviews, 1 single economic study was included (Abel et al.
28 2013, +), which was a prospective cohort study ($N=450$) and examined the cost-
29 effectiveness of ACP for individuals reaching end of life in a hospice in the South West of
30 England. They found that people who used ACP spent considerable less time in hospital in
31 their last year of life (IG 18.1 vs. CG 26.5 days, $p < 0.001$). Mean cost of hospital treatment
32 during the last year of life for those who died in hospital was GBP (Great Britain Pound)
33 11,299 and for those dying outside of hospital GBP 7,730; MD 3,569; $p < 0.001$. In this study,
34 ACP was defined as discussions taking place about place of death using the 'Planning
35 Ahead' document, which included general treatment preferences as well as advance
36 decisions. Both groups received specialist palliative care provided in hospice, which included
37 inpatient and outpatient services, visits from specialist palliative care community nurses at
38 home and a day care centre. Primary outcomes measures were: Place of death (including
39 whether person died in their preferred place of death for those who had expressed a
40 preference/ were part of ACP group). Costs included those from the hospital perspective
41 only. Results showed that 14 (75%) achieved their choice of place of death. For those who
42 chose home, 34 (11.3%) died in hospital; for those who chose a care home 2 (1.7%) died in
43 hospital; for those who chose a hospice 14 (11.2%) died in hospital; for those who chose to
44 die in hospital 6 (86%) did so. In the standard care group, 112 (26.5%) died in hospital.
45 Individuals in the intervention group spent significantly fewer days in hospital in the last year
46 of life (18.1% vs. 26.5%, $p < 0.001$), had a non-significantly ($p = 0.3$) lower mean number of
47 emergency admissions: 1.61 (95% CI 1.4 to 1.8) vs. 1.75 (95% CI 1.6 to 1.9). Mean costs for
48 emergency admissions were non-significantly ($p = 0.4$) lower in the intervention group versus
49 standard care: GBP 5,260 (95% CI 4,586 to 5,934) vs. GBP 5,691 (95% CI 4,984 to 6,398).
50 The mean cost of hospital treatment during the last year of life for those who died in hospital

1 was significantly higher for those dying in hospital: GBP 11,299 vs. GBP 7,730 (MD 3,569;
2 $p < 0.001$). Authors concluded that those who used ACP spent less time in hospital in their
3 last year and that ACP was associated with a reduction in the number of days in hospital in
4 the last year of life leading to fewer hospital costs. However, the study had a number of
5 limitations. Findings on costs were not presented for people receiving ACP versus those not
6 receiving ACP so that not final conclusions could be drawn about the overall cost impact of
7 ACP. In addition, the cost perspective was limited to hospital costs. The study was a cohort
8 study which only controlled for a very small number of variables so that effects might be
9 explained by other factors, such as whether the person had a carer or not. The study
10 referred to a very specific population, i.e. those who were accessing hospice services. This
11 is likely to present a small proportion of the overall population at the end of life (for example,
12 in England only 4% of older people die in a hospice).

13 Overall, from the economic evidence no final conclusions could be drawn about the cost-
14 effectiveness of ACP. Most of the economic evidence referred to cost savings studies from
15 the US. They referred to different types of interventions and had a limited cost perspective.
16 There was no study that evaluated the cost-effectiveness of ACP. More generally, due to the
17 nature of the intervention it was more difficult to identify RCTs or experimental studies. The
18 systematic review carried as part of this guideline identified a RCT from Australia, which
19 evaluated the effectiveness of ACP but did not measure costs (Detering et al. 2010).
20 Findings suggested that ACP could have a positive impact on people's health and wellbeing
21 outcomes, such as the quality of death experienced by persons dying; mental health of
22 carers; satisfaction of people dying and their carers with services. In addition, an England-
23 based retrospective cohort study (Dixon et al. 2016) measured the impact of ACP on place
24 of death in the general population and showed that there was association. In current English
25 practice, many people are not offered ACP and this has been criticised by those who think
26 there is sufficient evidence of its benefits to support its system-wide introduction (e.g.
27 Kononovas K and McGee A 2017). Cost-effectiveness is thus likely to be an important
28 source of evidence to inform recommendations. The guideline committee agreed that
29 additional economic analysis was valuable, appropriate and feasible (if data could be used
30 from the sources including Detering et al. 2010 and Dixon et al. 2016).

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33 2.2 Joint crisis planning (JCP)

34

35 Three economic studies were identified on Joint crisis planning (JCP), all of which were from
36 England (UK) and from the same group of researchers.

37 A single cost-effectiveness study (Flood et al. 2006, ++) in form of single blinded RCT
38 (N=160) examined the cost-effectiveness of JCP versus standardised service information
39 about the Mental Health Act (MHA), complaints procedures, access to case records and
40 treatment options. JCP included an introductory meeting at which a facilitator explained the
41 procedure to the person with mental illness and to their care coordinator; contents were
42 discussed and plan completed at a second meeting, which was also attended by a
43 psychiatrist. The study population referred to people of 16 years and above with clinical
44 diagnosis of psychotic illness or non-psychotic bipolar disorder, who were not currently
45 receiving inpatient care, and had experienced an admission in the previous 2 years. Primary
46 outcomes measures included admission to hospital; length of time spent in hospital.
47 Secondary outcome measures included objective coercion (i.e. compulsory treatment under

1 MHA 1983) and service use over 15 months. Findings suggested that, in terms of outcomes,
2 there was a significant reduction in use of MHA (=compulsory admission) in the intervention
3 versus control group (13% vs. 27%, RR 0.48, 95% CI 0.24 to 0.95, P = 0.03) and a non-
4 significant reduction in hospital admissions (RR 0.69, 95% CI 0.45 to 1.04, P = 0.07). In
5 terms of total mean costs at 15 months those were non-significantly lower in the intervention
6 group (GBP 7,264 vs. GBP 8,359; MD GBP 1,095; 95% CI -2814 to 5004; P = 0.57). Cost
7 effectiveness acceptability curves suggested there was a greater than 78% probability that
8 JCP was more cost effective than standardised service information in reducing the
9 proportion of patients admitted to hospital

10 A large multi-centre RCT (Barrett et al. 2013, ++; N=540) evaluated the cost-effectiveness of
11 a similar JCP intervention described in Flood et al. (2006) with the aim to substantiate the
12 findings. JCP included an introductory meeting at which a facilitator explained the procedure
13 to the person with mental illness and to their care coordinator; contents were discussed and
14 a plan completed at a second meeting, which was also attended by a psychiatrist. In
15 addition, the person was contacted by the facilitator 9 months later to check if (s)he wanted
16 to update the JCP. The study population referred to persons of 16 years or above and who
17 had at least 1 psychiatric admission in the previous 2 years and who were registered on the
18 Enhanced Care Programme Approach register. Primary outcomes measures at 18 months
19 were admission to hospital under the Mental Health Act. Secondary outcome measures were
20 not reported in this study but in the main study (Thornicroft et al. 2013). In terms of outcomes
21 measured at 18 months, there was no significant reduction compulsory admission (OR 0.90,
22 95% CI 0.59 to 1.38, p = 0.63) and no significant treatment effects for any other admission
23 outcomes, although there was evidence for improved therapeutic relationships in the
24 intervention arm, described in detail in the main paper by Thornicroft et al. (2013). In terms
25 of total public-sector costs, there was no significant reduction in the intervention group
26 compared with the control group: GBP 17,233 (SD 21,013) versus GBP 19,217 (SD 28,133).
27 The mean difference (MD) was GBP -1,994 (95% CI -5,733 to 2,248; p=0.414). There was
28 no significant reduction in costs from a societal perspective (which included productivity
29 losses and criminal activity): GBP 22,501 (SD 28,103) versus GBP 22,851 (SD 34,532). The
30 mean difference was GBP -350 (95% CI -4,727 to 5,404; p = 0.902). Findings showed that
31 JCP had 80% probability of cost-effectiveness from public sector perspective (and around
32 44% from a societal perspective).

33 In subgroup analyses it was found that for the Black and Black British population the
34 intervention was achieving higher cost-effectiveness: The primary outcome (=compulsory
35 admissions) was significantly lower in the intervention subgroup (20%, N=66) compared with
36 the control subgroup (32%, N=72) with a mean difference of 0.553 (95% CI 0.249 to 1.226;
37 p=0.256). Mean public sector costs in the intervention group were non-significantly lower in
38 the intervention group: GBP 17,628 (SD 25,163) versus GBP 28,377 (SD 36,627). The mean
39 difference was GBP 10,749 (95% CI -20,387 to 536; p=0.079). Mean societal costs were
40 also non-significantly lower in the intervention group: GBP 23,150 (SD 29,588) vs. GBP
41 32,780 (SD 41,170) with a mean difference of GBP 9,630 (95% CI -21,043 to 3,106;
42 p=0.16). Findings suggested that the intervention was cost-effective from a public-sector
43 perspective but this was attributed to the high cost-effectiveness in Black ethnic groups.

44 A small feasibility cost consequences and utility study (Borschmann et al. 2013, ++, N=88),
45 which was carried out alongside a pilot RCT, examined the cost consequences of JCP
46 versus standard care for people living with borderline personality disorder. The intervention
47 was the same as described before (Flood et al. 2006; Barrett et al. 2013) and included: an
48 introductory meeting with facilitator, who explained the procedure to person and care
49 coordinator; contents of the plan were discussed and completed by facilitator at second

1 meeting which was attended by the person, care coordinator, and psychiatrist. The
2 population referred to persons of 18 years and above with a diagnosis of borderline
3 personality disorder, who had self-harmed in past year, were under the ongoing care of a
4 community mental health team and able to give informed consent. Primary outcomes
5 measures included the occurrence of self-harming behaviour at 6 months and secondary
6 outcome measure included depression, anxiety, engagement, satisfaction with services,
7 quality of life, wellbeing and cost-effectiveness. There were no significant differences
8 between the groups on any of the secondary outcome measures at follow-up. Quality
9 adjusted life years gained (QALYs) were presented in the online supplement as they were
10 considered only hypothesis generating: 0.31 (SD 0.11) vs. 0.30 (SD 0.15). The mean cost of
11 the intervention was GBP 146 per participant and there were no significant differences in
12 mean total health and social care costs (GBP 5,631 versus GBP 5,308, P = 0.20). In the
13 online supplement, an ICER of GBP -32,358 suggesting that JCP dominated standard care.
14 In summary, the study found that individuals with borderline personality disorder, who self-
15 harmed in the last year and were under ongoing care of a community mental health team,
16 had no significant changes in any of the outcomes (including self-harm and QALY at 6
17 month); there was no significant difference in mean costs; the incremental cost-effectiveness
18 ratio was GPB -32,358 suggesting that JCP was less costly and more effective than
19 standard care.

20 Altogether, from the 3 studies it could be concluded that there is a small amount of high
21 quality economic evidence that joint crisis plans (JCP) for people with psychosis and
22 borderline personality disorder can lead to reductions in compulsory treatment under the
23 Mental Health Act and be cost-effective from a public-sector perspective. It was suggested
24 that people with psychosis from Black minority groups might benefit more than other
25 populations from JCP and that JCP was likely to be particularly cost-effective for this
26 population.

27 The guideline committee agreed that the additional value of doing further economic analysis
28 was limited: Additional economic analysis would have been useful, for example, if there was
29 an expected long-term impact of JCP, which had not been captured in the existing 3 studies.
30 There was, however, no evidence of a long-term impact. Since JCP is a time-limited
31 process, the short-term perspective of economic evaluation as chosen in the 3 studies was
32 thus considered appropriate. The quality of the 3 economic studies was high. This included a
33 comprehensive cost perspective, the measurement of QALYs and substantial sensitivity
34 analysis to present the uncertainty around the ICER. The probability that additional analysis
35 would have shielded new findings on the cost-effectiveness of JCP was thus considered low
36 and the guideline committee agreed base recommendation on the existing economic
37 evidence from those 3 studies (in addition to evidence on effectiveness, views and
38 experiences in regards to JCP).

39

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41 3 Additional economic analysis of ACP: General approach

42

43 It was agreed with the guideline committee to carry out additional economic analysis of ACP
44 using decision modelling. The aim was to examine the cost-effectiveness of advance care
45 planning provided at the end of life in an English context. The guideline committee agreed
46 that it was important that the intervention referred to the offer of ACP and not the uptake, as
47 not everyone wished to participate in ACP and it was important to recognise the choice

1 people had. Standard care referred to not being offered ACP. It was agreed with the
2 guideline committee to focus the model on older people in the final year of life, which was a
3 large and important group of the population covered in the scope. It was difficult to define the
4 age as evidence related to different age groups. For example, the population in Detering et
5 al. (2010) referred to older people above 80 years and the mean age was 85 years. While
6 important sub groups included people with dementia and with cancer, the guideline
7 committee agreed to focus on the general population of people towards end of life so that
8 findings related to the majority of older people. Expected impact on costs and outcomes was
9 likely to be different for people with cancer or with dementia. The guideline committee
10 agreed to not prioritise dementia in the economic work because the majority of studies,
11 which evaluated ACP for people with dementia, referred to people living in a care home with
12 already advanced stages of dementia. Latest evidence suggests that providing ACP at this
13 point might not be good practice; instead ACP might be better provided at an early stage of
14 dementia and take place in memory clinics or community mental health teams (Robinson et
15 al. 2012; Poppe et al. 2013). The guideline committee agreed that while it was important that
16 – in the absence of better knowledge – ACP was offered to people with advanced dementia
17 and their carers, the economic work should focus on a population, for which ACP was known
18 to reflect good practice. In terms of people with cancer, there was not sufficient data to
19 develop a separate model. It is possible that ACP is more cost-effective for this group as
20 they use potentially more services towards end of life such as chemotherapy. However,
21 there was not enough data to examine this in more detail.

22 The guideline committee discussed that ACP should be offered in different settings in which
23 people age, including in hospital and the community. It was agreed with the guideline
24 committee to not prioritise the hospice setting as the population using hospice at the end of
25 life is small and evidence already existed, which showed that ACP as part of hospice care is
26 likely to be cost-effective (Abel et al. 2013). The guideline committee discussed where ACP
27 should be carried out; it was agreed that it was not appropriate to narrow down the setting,
28 and instead use an evaluation approach that would ensure findings were likely to apply to
29 different settings. It was noted, however, that there was currently a gap in the evidence
30 about the role of ambulance services in ACP.

31 Cost-utility analysis appeared to be the most appropriate type of analysis as there was
32 evidence of an impact of ACP on health-related quality of life on persons dying and their
33 carers (this is examined in detail in section 6). Cost-utility analysis compares the difference
34 in costs in both groups (ACP vs. standard care) with the difference in health-related quality
35 of life outcomes in both groups (ACP vs. standard care). Cost differences include the costs
36 of implementing a programme or intervention (here: ACP) as well as costs linked to resource
37 use, which is affected by the intervention (=economic consequences). In this analysis,
38 resource use referred to the use of government-funded health and social care services, as
39 the perspective taken was the one of the NHS and Personal Social Services (PSS). In cost-
40 utility analysis, health-related quality of life is expressed in quality adjusted life years gained
41 (QALY), so that findings are expressed in costs per QALY. The measure used to express
42 findings is called the incremental cost effectiveness ratios ICER. Cost-utility analysis is the
43 preferred economic evaluation type as it allows making a decision about cost-effectiveness
44 based on incremental cost effectiveness ratios (ICER). The ICER can be used to assist
45 decision-making based on threshold values of cost per QALY. ICER values below ranges of
46 £20,000 to £30,000 per QALY are usually considered to indicate the cost-effectiveness of an
47 intervention.

48 The model was a decision tree. This was considered most appropriate, as the time period
49 covered by the model was a short-term one of about 1 year. The literature on ACP did not

1 provide information on repeating events so that a decision model (rather than Markov model)
2 was chosen. While most of the costs and outcomes were likely to occur towards the end of
3 life, the model needed to cover the whole duration of the intervention. The guideline
4 committee agreed that ACP that follows good practice is an ongoing process; the
5 assumption made in this analysis was that it occurred at different time points during the
6 maximum period of 1 year before death. It is possible that ACP discussions take place over
7 a longer time period but no further information was available on this. For some conditions, in
8 particular dementia, ACP might take place earlier; for example, it has been suggested that
9 for dementia it needs to be as early as after diagnosis (Robinson et al. 2012; Poppe et al.
10 2013). However, the focus here was on people with conditions other than (moderate to
11 severe) dementia. Discounting was not applied, as the model was a short-term one of 1 year
12 or less. The cost perspective was the one of the NHS and Personal Social Services (PSS),
13 and all costs were presented in 2015/16 prices.

14 Probabilistic sensitivity analysis (PSA) was carried out for all parameters unless stated
15 otherwise. In PSA, the full value range rather than a single value is considered for each
16 parameter. This was done by determining the distributions that a value could take for each
17 parameter and then running a large number (here 1000) of Monte Carlo simulations, which
18 produced the results of different combinations of random draws. The choice of distributions
19 followed standard practice (Sculpher 2004). Briefly, these were as follows: beta distribution
20 for probability parameters, gamma distribution for cost and utility parameters and normal
21 distributions for parameters that reflected intervention effects. In addition, one-way and two-
22 ways sensitivity analysis was carried for values that were particularly uncertain and where
23 much higher or lower values were explored to understand the impact of this change on the
24 ICER. It is important to note that these one-way or two-ways sensitivity analyses were run
25 stochastically and the parameters of interest was subject to the full uncertainty under PSA by
26 effectively shifting the entire distribution.

27 A range of data sources were used to inform the model parameters. Costs of delivering ACP
28 were based on resource inputs, which were estimated in consultation with a sub group of the
29 guideline committee through an iterative process. National unit costs (such as from PSSRU
30 Unit Costs for Health and Social Care 2016; Curtis L and Burns A 2016) were assigned to
31 resource inputs. The guideline committee's estimates of resource inputs were informed by
32 evidence and national guidance. The process of how the costs of ACP were derived is
33 described in sections 3.1 and 3.2. Cost consequences were based on relative effect sizes,
34 which measured the relative difference in service use outcomes between ACP and standard
35 care. Relative effect sizes were taken primarily taken from Detering et al. (2010) and referred
36 to service use outcomes of cardiopulmonary resuscitation (CPR), (other) life-prolonging
37 treatment (in form of assisted ventilation) and place of death. Data on the effect of ACP on
38 place of death were primarily taken from a recent English retrospective cohort study (Dixon
39 et al. 2016). A wide range of data source from England were used to inform parameters in
40 standard care. Effects in the ACP group were calculated based on data for standard care
41 from England and relative effect sizes from Detering et al. (2010) and Dixon et al. (2016).
42 Data on standard care were taken from national statistics and national reports (such as the
43 End of Life Care Audit and National Enquiry into Patient Outcomes and Deaths). Unit costs
44 were assigned to service use (cardiopulmonary resuscitation, assisted ventilation and place
45 of death) based on national sources such as PSSRU Unit Costs for Health and Social Care
46 2016, National Schedule of Reference Costs, and on peer-reviewed papers of single studies.
47 Finally, the impact of ACP on health-related quality of life was measured based on outcomes
48 measured in the Detering et al. (2010). Outcomes were converted into health utilities based
49 on English data from Roberts et al. (2014). Assumptions were made about the duration over
50 which the change in health-related quality of life lasted. For each of the economic

1 consequences a summary of the evidence is provided sections 5.1 to 5.3. This sets out the
2 logical pathway, in which APC is thought to influence service use outcomes and health-
3 related quality of life. This is followed by a detailed description of the methods used to
4 calculate each of the economic consequences, including the parameters and data that
5 informed the calculation. Finally, the calculation of QALY as health outcomes is described in
6 section 6.

7 4 Costs of Advance Care Planning

8

9 4.1 Method

10

11 The cost of ACP for older people in their last year of life was assessed in an iterative
12 process in close collaboration with a sub group of the guideline committee, which consisted
13 of 6 members. In addition, discussions took place with the whole guideline committee, which
14 were also informed about the work of the sub group and any decisions made.

15 In the consultation with the sub group semi-structured questionnaires were employed. The
16 consultation was an iterative process. First, a questionnaire was sent to members of the sub
17 group, which asked questions about the process of ACP, about the involvement of different
18 professionals in the process and about training. The initial questionnaire had been informed
19 by the literature on ACP and previous discussions by guideline committee members. Based
20 on the responses, a questionnaire was developed with more detailed questions about the
21 duration of the process, the time each professional spent on the process; members of the
22 sub group were asked to specify the average, minimum and maximum time each
23 professional spent on the process; this also included questions about the estimated
24 probabilities that involvement of professionals was required.

25 The guideline committee was informed about the progress of the sub group at 2 meetings. In
26 the following, information provided by the sub group are referred to as made by the guideline
27 committee since the sub group had been trusted with this task on behalf of the whole group.

28

29 4.2 Findings

30

31 The process of ACP for older people in the last year of life included 3 elements:

- 32 1) The identification of persons who could benefit from ACP
- 33 2) Mental capacity assessment in relation to ACP
- 34 3) ACP discussions as the main part

35 While the 2 first steps were not always a distinct part of ACP and were sometimes already
36 included in existing processes and infrastructure, it was agreed with the guideline committee
37 to include them in the costing. This helped to ensure the cost estimates were realistic and
38 not underestimating the actual costs that would occur in some localities, in which such
39 processes had not yet taken place.

40

41 4.2.1 Identifying persons who would benefit from ACP

42

1 The process of ACP included identifying persons who might benefit from ACP as well as the
2 identification of a Lasting Power of Attorney (if appropriate). The guideline committee agreed
3 that the identification should be done by the main professional contact of the person, who
4 would typically be a care coordinator or someone who had taken on a similar role. This
5 would be the same person who would also lead on the other 2 steps of the process, mental
6 capacity assessment and ACP discussion.

7 The guideline committee thought that while the main contact could be a person from different
8 professional backgrounds, most often this referred to a nurse or someone on a similar band.

9 In 2009, the Royal College of Physicians (2009) recommended that a community matron or
10 specialist nurse should carry out ACP. Based on job titles this would refer to Bands 6 to 8a
11 for hospital nurses (and Band 7 for community nurses). The guideline committee members
12 agreed that those bands were generally appropriate although they thought Band 8 nurse
13 was less likely to carry out ACP activities whereas they thought that a nurse on Band 5
14 (midpoint) could carry out ACP since the job role of a Band 5 nurse included 'establishing
15 effective working relationships with patients, their families and carers. This will include
16 promoting individual rights and recognising and respecting their contributions to care
17 planning and delivery'. Some guideline committee members thought that it was reasonable
18 to set out that a Band 5 nurse should do ACP. The guideline committee debated the
19 appropriate Band extensively and finally agreed that ACP should be done by a Band 5 or 6
20 nurse, but not by a Band 7 or 8 nurse. They also thought that it was important to emphasise
21 that social care as well as healthcare staff should be competent and active in undertaking
22 ACP.

23 The guideline committee estimated that the identification would take between 1 to 15
24 minutes. Generally, guideline committee members thought that the question of identification
25 was more one of effective processes in place than one of costs. Effective processes would
26 ensure that persons would be asked based on certain circumstances.

27 The guideline committee thought that based on literature from Emanuel et al. (2000), Mullick
28 et al. (2013), Henry and Seymour, there were certain events that should prompt the main
29 contact to ask about ACP, including:

- 30 • Life-threatening illness
- 31 • Significant change in health status and unexpected illness (including major trauma)
- 32 • Illnesses that will predictably have significant impact on a person's cognition
- 33 • Assessment of need (e.g. needs assessment under s.9 *Care Act 2014*)
- 34 • Multiple hospital admissions
- 35 • Patient initiates the conversation
- 36 • Diagnosis of a progressive life limiting illness
- 37 • The diagnosis of a condition with a predictable trajectory, which is likely to result in a
38 loss of capacity, such as dementia or motor neurone disease
- 39 • A change or deterioration in condition
- 40 • Change in a patient's personal circumstances, such as moving into a care home or
41 loss of a family member
- 42 • Routine clinical review of the patient, such as clinic appointments or home visits
- 43 • When the previously agreed review interval elapses

44 The guideline committee discussed the possible involvement of an advocate at this stage: It
45 was possible that an advocate would be present already during the identification process
46 although they would not have a defined reason at that point; this could be an Independent
47 Care and Support Advocate under the *Care Act 2014* who would be there during

1 assessments (of social care needs) or during reviews of a care and support plan; another
 2 possibility was that an Independent Mental Health Advocate was supporting the person in a
 3 situation where the Mental Health Act was used.

4 The guideline committee thus decided that the cost of an advocate should be included for
 5 those circumstances and the probability that an advocate was present was estimated to be
 6 between 5% and 25%. A midpoint of a 15% was then assumed.

7 Costs were calculated by multiplying the duration of the process by the probabilities for the
 8 main contact and advocate to be required at the meeting and by respective unit costs.
 9 Values for all parameters are summarised in Table 1. The cost for the identification of
 10 someone who might benefit from ACP was £87 per person. Estimates ranged from £44 to
 11 £139.

12

13 Table 1: Parameters and values for costing 1. Element of ACP process: identification of
 14 person who might benefit from ACP

Parameter	Mean or deterministic value	Range	Source and details
Duration of process of identifying a person (in hours)	0.13	0.02 to 0.25	GC estimate
Main contact			
- Probability that person required	100%		GC estimate
- Unit cost per hour (in £)	75.6	43.2 to 108	PSSRU (2016), range derived from community nurse Band 5 to 6, refers to working hour (£36 to £44) multiplied with 1.2 to reflect face-to-face time (so that £43.2 to £52.8); hospital-based nurse Band 5 to 6, face-to-face time (£86 to 108)
Advocate			
- Probability that professional attends the meeting	15%	5% to 25%	GC estimate
- Unit cost per hour (in £)	58		PSSRU (2016), p. 58; refers to client related time of advocate for parents with learning disabilities

15

16

17 **4.2.2 Mental capacity assessment in relation to ACP**
 18

19 Next, it was agreed that for some persons a Mental Capacity Assessment would need to be
 20 carried out as part of the ACP process. This referred in particular to assessing the mental
 21 capacity of a person to make legally binding advance decisions and decisions about
 22 assigning a Lasting Power of Attorney (LPA). The guideline committee thought it was
 23 important to emphasise that while the assessment of mental capacity started from the

1 assumption of capacity, considering the assessment of mental capacity was an important
 2 process of ACP since decisions related to treatment and care and thus required consent
 3 from every person. Some guideline committee members highlighted the important impact on
 4 later ACP outcomes if this process was not carefully considered. For example, sometimes
 5 ACP wishes were not adhered to because professionals doubted that the person had full
 6 capacity to make such decisions. However, it was unclear how such negative outcomes
 7 could be prevented and it was beyond the scope of this analysis to explore the potential
 8 impact of mental capacity assessments as part ACP.

9 The guideline committee estimated that a formal assessment of capacity was required for
 10 10% to 25% of people engaged in ACP. The midpoint of 17.5% was chosen as a mean
 11 value. It was agreed that the main contact should usually be carrying out such the
 12 assessment if it was specific to the decisions made under ACP, and the guideline committee
 13 estimated that the process would take between 1 and 2.5 hours. A midpoint of 1.75 hours
 14 was taken as a mean. Values for all parameters are shown in Table 2. The mean cost of this
 15 part of the process was £23.15, with a minimum cost of £4.32 and a maximum cost of £67.5.

16 The guideline committee also discussed the involvement of other persons and professionals
 17 in the assessment of mental capacity. Whether or not other persons attended the
 18 assessment strongly depended on the individual situation and on who the person wanted to
 19 be there. This could include family members as well as some professionals, who might need
 20 to be contacted for specialist advice. For the analysis, it was thus not possible to include
 21 further costs in relation to the involvement of other professionals.

22

23 Table 2: Parameters and values for costing 2. Element of ACP process: Mental capacity
 24 assessment in relation to ACP

Parameter	Mean or deterministic value	Range	Source and details
Probability that mental capacity assessment in relation to ACP required	17.5%	10% to 25%	GC estimate
Duration of process of assessing person's mental capacity (in hours)	1.75	1 to 2.5	GC estimate
Main contact			
- Probability that person required	100%		GC estimate
- Unit cost per hour (in £)	75.6	43.2 to 108	PSSRU (2016), range derived from community nurse Band 5 to 6, refers to working hour (£36 to £44) multiplied with 1.2 to reflect face-to-face time (so that £43.2 to £52.8); hospital-based nurse Band 5 to 6, face-to-face time (£86 to 108)

25

26

27 **4.2.3 ACP discussions (including training)**

28

1 Regarding the actual ACP discussions as the main element of ACP, the guideline committee
 2 agreed that those were typically part of an ongoing process, which could include a number of
 3 reviews, during which the person could revise their wishes. The guideline committee
 4 estimated that the process of ACP discussions could last between 10 minutes and 8 hours.
 5 The guideline committee considered evidence from the study by Detering et al. (2010),
 6 which found that the minimum time was 10 minutes and the maximum time was 2 hours
 7 (average time was 1 hour). However, some guideline committee members thought that for
 8 complex cases the discussion could take up to 8 hours. There was considerable debate
 9 about an appropriate mean estimate. In particular, the guideline committee discussed
 10 whether a realistic mean should be lower than the average between the estimated minimum
 11 and maximum times (as the 8 hours referred to particularly complex cases). Some members
 12 thought that 2 hours was a more realistic mean, which would also reflect that time pressures
 13 in current practice might demand on average shorter discussions of 2 hours. It was decided
 14 to take the mean estimate of 4 hours in the base case scenario and to explore in (one and
 15 two ways) sensitivity analysis the impact of a lower mean estimate of 2 hours on findings.

16 The guideline committee discussed the role of an advocate, who supported the person
 17 through the ACP discussions; under the Mental Health Act this would be an Independent
 18 Mental Health Advocate, who would support the person with their understanding of consent
 19 to treatment and their wishes for future care and involvement in the ACP. The guideline
 20 committee thought that an Independent Mental Capacity Advocate could also potentially be
 21 involved in ACP discussions for short periods; this was, for example, possible when
 22 instructed by the main contact under the Mental Capacity Act in situations where the person
 23 had fluctuating capacity. The guideline committee also discussed the role of Lasting Power
 24 of Attorney, which was usually an unpaid person; while in the majority of times the person
 25 would be unpaid, there would be a few exceptions where the Lasting Power of Attorney
 26 would be a paid solicitor

27 The guideline committee agreed the involvements of professionals in ACP discussions, the
 28 probability that they were required at ACP discussions and the time they would need to be
 29 involved. Values for all parameters included the cost of ACP discussions are shown in Table
 30 3. The mean cost of this part of the process was £694, with a minimum cost of £161 and a
 31 maximum cost of £1,638. This did not yet include the costs of training that professionals
 32 required in order to participate in ACP discussions.

33

34

35 Table 3: Parameters and values for costing 3. Element of ACP process: ACP discussions –
 36 Training not included

	Mean	Range	Source and details
Main contact			
- Probability that person required	100%		GC estimate
- Time required (in hrs)	4.08	0.17 to 8	GC estimate; this referred to the overall time required for the ACP process
- Unit cost per hour (in £)	75.6	43.2 to 108	PSSRU (2016), range derived from community nurse Band 5 to 6, refers to working hour (£36 to £44) multiplied with 1.2 to reflect face-to-face time;

			Hospital-based nurse Band 5 to 6, face-to-face time (£86 to 108)
Clinician			
- Probability that clinician required	50%	25% to 100%	GC estimate
- Time required (in hrs)	0.82		GC estimate, refers to 20% of mean time of ACP discussions
- Unit cost per hour (in £)	148.5	135 to 162	PSSRU (2016); p.191; refers to unit of medical consultant, which reflects unit cost of specialty doctor (HSCIC 2016); costs were multiplied with 1.2 to reflect face-to-face time
Advocate			
- Probability that advocate required	13.5%	2% to 25%	GC estimate
- Time required (in hrs)	4.08		GC estimate; refers to mean time of ACP discussion discussions
- Unit cost per hour (in £)	58		PSSRU (2016), p.58; refers to client related time of advocate for parents with learning disabilities
Lasting Power of Attorney (LPA)			
- Probability that LPA required	32.5%	0.05% to 6%	GC estimate
- Time required (in hrs)	4.08		GC estimate; refers to mean time of ACP discussion discussions
- Probability that LPA was paid solicitor	1.95%	0.03% to 3.6%	GC estimate and Beckett et al. (2014)
- Unit cost per hour (in £)	100		GC estimate
Social worker			
- Probability that social worker required	40%	20% to 60%	GC estimate
- Time required (in hrs)	3.06	2.04 to 4.08	GC estimate; range refers to 50% to 100% of mean time of ACP discussions, and mean reflects midpoint
- Unit cost per hour (in £)	67	55 to 79	PSSRU (2016), p.156; refers to face-to-face time of social worker (adults)
Occupational therapist			
- Probability that occupational therapist required	22.5%	20% to 25%	GC estimate
- Time required (in hrs)	3.06	2.04 to 4.08	GC estimate; range refers to 50% to 100% of mean time of ACP discussions, and mean reflects midpoint
- Unit cost per hour (in £)	48.4	44 to 52.8	PSSRU (2016), p.159; no client-related work or face-to-face time available so that unit cost was multiplied with 1.2

Speech and language therapist			
- Probability that speech and language therapist required	22.5%	20% to 25%	GC estimate
- Time required (in hrs)	3.06	2.04 to 4.08	GC estimate; range refers to 50% to 100% of mean time of ACP discussions, and mean reflects midpoint
- Unit cost per hour (in £)	48.4	44 to 52.8	PSSRU (2016), p.184; no client-related work or face-to-face time available so that unit cost was multiplied with 1.2
Psychologist			
- Probability that psychologist required	22.5%	20% to 25%	GC estimate
- Time required (in hrs)	3.06	2.04 to 4.08	GC estimate; range refers to 50% to 100% of mean time of ACP discussions, and mean reflects midpoint
- Unit cost per hour (in £)	120.1	99.3 to 140.9	PSSRU (2015), p.90; reflects average between Band 8 median clinical psychologist and Band 6 median mental health nurse; uprated with PPI to 2016 prices
Psychiatrist			
- Probability that psychiatrist required	5.5%	1% to 10%	GC estimate
- Time required (in hrs)	2.45	0.82 to 4.08	GC estimate; range refers to 20% to 100% of mean time of ACP discussions, and mean reflects midpoint
- Unit cost per hour (in £)	151.8	138 to 165.6	PSSRU (2016), p.191, refers to psychiatric consultant (hospital); multiplied with 1.2 to reflect face-to-face time
GP			
- Probability that GP required	5.5%	1% to 10%	GC estimate
- Time required (in hrs)	3.06	2.04 to 4.08	GC estimate; range refers to 50% to 100% of mean time of ACP discussions, and mean reflects midpoint
- Unit cost per hour (in £)	122.5	111 to 134	PSSRU (2016), p.145; GP unit cost estimate excluding direct care staff costs

1

2

3 In terms of training for professionals who were participating in ACP discussions, the
4 guideline committee agreed that half-day ACP training should inform the costing; this was
5 also suggested in Detering et al. (2010), which referred to the 'Respecting Choices' model, a
6 commonly used training programme for ACP that is available internationally.

1 Training in practice was organised and provided either by a trained facilitator, who was
 2 employed as a practitioner by the NHS or Local Authority, but had taken on the training
 3 function as part of their role, or by an external, independent trainer. The cost of training
 4 following the first approach is strongly dependent on the unit cost of the person providing the
 5 training and the time required for planning the training, which could vary substantially by
 6 different localities. Estimating the cost of training following the second approach was thus
 7 considered more appropriate as it could be estimated based on fees charged by external
 8 trainers available to most localities for the same fee. As a mean estimate a fee of £200 for
 9 half day of training was taken; this referred according to guideline committee members to
 10 what independent trainers accredited by an Approved Mental Health Professionals (AMHPS)
 11 and Best Interest Assessor (BIA) Team would charge. A maximum estimate of £300 was
 12 taken, which referred to a full day training provided by Hospice UK¹, which also included
 13 training for Mental Capacity Assessment. A minimum estimate of £184 was taken, which
 14 reflected the prices of Respecting Choices training as provided in Australia when converted
 15 in UK pounds².

16 Training costs for each professional involved in the ACP discussions was calculated as
 17 follows. First, the cost of training per participating professional was calculated. This referred
 18 to the cost of providing training as well as the cost of staff time for attending the training. The
 19 cost of providing training per participant was calculated based on the training fees mentioned
 20 above, divided by the number of participants. Next, the staff costs for attending training were
 21 calculated by multiplying the number of hours of training with the unit cost for each
 22 professional. Finally, to allocate costs to an ACP discussion it was assumed that training
 23 lasted for 50 deliveries. Table 3 shows the parameters and values used to inform the costs
 24 of training.

25

26 Table 3: Parameters and values for costing training as part 3. Element of ACP process: ACP
 27 discussions

Parameter	Mean	Range	Source and details
Cost of training course (in £)	200	184 to 300	Based on fees charged by independent trainers
No. of participants per course	7	6 to 8	GC estimate
Fee per person attending (in £)	28.57	30.7 to 37.5	Calculated from cost of training course; range reflects lower cost of training divided by higher no. of participants and higher cost of training divided by lower no. of participants; mean estimate reflects mean cost divided by mean no. of participants
Length of training (in hours)	4		GC estimate
Main contact			
- Cost for staff time per training	302.4	172.8 to 432	Calculated; unit cost multiplied with 4hrs

¹ <https://supporter.hospiceuk.org/public/event/eventBooking.aspx?id=EVT00524>

² <https://www.advancecareplanning.org.au/education-and-training>

- Cost of attending course and staff time per ACP discussion	6.62	3.92 to 9.64	Cost of staff time per training and cost of training per participants divided by 50; assumed 50 deliveries before refresher training would need to be provided
Advocate/ IMCA			
- Cost for staff time per training	232		Calculated; unit cost multiplied with 4hrs
- Cost of attending course and staff time per ACP discussion	5.21	5.1 to 5.64	Cost of staff time per training and cost of training per participants divided by 50; assumed 50 deliveries before refresher training would need to be provided
Clinician			
- Cost for staff time per training	594	540 to 648	Calculated; unit cost multiplied with 4hrs
- Cost of attending course and staff time per ACP discussion	12.45	11.26 to 13.96	Cost of staff time per training and cost of training per participants divided by 50; assumed 50 deliveries before refresher training would need to be provided
Social worker			
- Cost for staff time per training	268	220 to 316	Calculated; unit cost multiplied with 4hrs
- Cost of attending course and staff time per ACP discussion	5.93	4.86 to 7.32	Cost of staff time per training and cost of training per participants divided by 50; assumed 50 deliveries before refresher training would need to be provided
Occupational therapist			
- Cost for staff time per training	193.6	176 to 211.2	Calculated; unit cost multiplied with 4hrs
- Cost of attending course and staff time per ACP discussion	4.44	3.98 to 5.22	Cost of staff time per training and cost of training per participants divided by 50; assumed 50 deliveries before refresher training would need to be provided
Speech and language therapist			
- Cost for staff time per training	193.6	176 to 211.2	Calculated; unit cost multiplied with 4hrs
- Cost of attending course and staff time per ACP discussion	4.44	3.98 to 5.22	Cost of staff time per training and cost of training per participants divided by 50; assumed 50 deliveries before refresher training would need to be provided
Psychologist			
- Cost for staff time per training	490	444 to 536	Calculated; unit cost multiplied with 4hrs

- Cost of attending course and staff time per ACP discussion	10.37	9.34 to 11.72	Cost of staff time per training and cost of training per participants divided by 50; assumed 50 deliveries before refresher training would need to be provided
Psychiatrist			
- Cost for staff time per training	607.2	552 to 662.4	Calculated; unit cost multiplied with 4hrs
- Cost of attending course and staff time per ACP discussion	12.72	11.5 to 14.25	Cost of staff time per training and cost of training per participants divided by 50; assumed 50 deliveries before refresher training would need to be provided
GP			
- Cost for staff time per training	490	444 to 536	Calculated; unit cost multiplied with 4hrs
- Cost of attending course and staff time per ACP discussion	10.37	9.34 to 11.72	Cost of staff time per training and cost of training per participants divided by 50; assumed 50 deliveries before refresher training would need to be provided

1

2 The costs of training were then allocated to an ACP discussion by multiplying the cost (fee)
3 for attending the training course and cost of staff time per ACP discussion by the probability
4 that the professional was involved in the ACP discussions. This was done for each
5 professional. The mean total cost of training per ACP session was £18, the minimum cost
6 was £5 and the maximum cost was £31.

7 In addition to the training to carry out ACP, the guideline committee thought that ACP also
8 required that staff had received other training (such as on information sharing and data
9 recording) and that some general awareness raising would take place. However, the
10 guideline committee agreed that, while it was important that those were provided, the costs
11 of those should not be allocated to the costs of ACP as those were part of general staff
12 training and organisational procedures.

13

14 **Total cost of ACP**

15 The total mean cost of ACP was £821 with a minimum cost of £214 and a maximum cost of
16 £1,874.

17

18 **5. Cost consequences**

19

20 **5.1 Cardiopulmonary resuscitation (CPR)**

21

1 There was evidence that older people are getting CPR inappropriately, and that ACP might
2 be able to reduce the number of inappropriate CPR by increasing the probability that a
3 person expresses their wishes of Do Not Attempt Cardio Pulmonary Resuscitation
4 (DNACPR) and that the person's wishes are followed:

- 5 • A report by the National Confidential Enquiry into Patient Outcome and Death
6 (NCEPOD 2012, p11) found that a high proportion of in-hospital deaths in England
7 and Wales involved CPR attempts, even when the underlying condition and general
8 health suggested this was not appropriate (i.e. CPR did not promise survival to
9 discharge and was only prolonging the dying process). Furthermore, the study found
10 that the CPR status was not well documented. For example, for only 10% of people
11 who had a cardiac arrest in hospital, decisions about CPR status were documented.
12 In addition, the report showed that some people were resuscitated despite a
13 DNACPR decision. While the study did not focus on older people specifically, the
14 mean age of the sample was 77 years (inter-quartile range 68 to 84), so that findings
15 were applicable.
16
- 17 • It is likely that ACP can help to prevent some of those inappropriate CPRs through
18 the following mechanisms: Most people have unrealistic positive beliefs about the
19 likelihood of survival after CPR, rating the probability of survival as high as 50:50
20 whereas the real chance is more towards 15%, and this includes people who will
21 have a severe disability after cardiac arrest or might live only for a short while
22 (NCEPOD 2012 p5; Hirschman and Schelternak 2000). ACP involves discussions, in
23 which the person is provided with information about this kind of evidence and people
24 as a result might express a wish of DNACPR. Wishes might also be more likely to be
25 followed for a person who expressed a DNACPR wish during the process of ACP
26 than for a person who expressed the wish without ACP.
27
- 28 • While evaluations of ACP in the UK have not measured this outcome, intervention
29 studies from the US have shown that people who get ACP were significantly more
30 likely to complete a DNACPR (e.g. Wright et al. 2008: 63% vs. 28.5%; adjusted odds
31 ratio 3.12 95% CI 1.98 to 4.90). They were also less likely to be resuscitated in last
32 week of life although this outcome was not always significant at a p-value of 0.05 or
33 95% CI (Wright et al. 2008: 0.8% vs. 6.7%; adjusted odds ratio 0.16 95% 0.03 to
34 0.80; Zhang et al. 2009: 1.4% vs. 8.7%; adjusted odds ratio 0.02 to 1.3, p=0.09).
35 Nicholas et al. (2011) showed that effect was more likely to be significant when ACP
36 was provided in areas, in which best interest decision-making would be different from
37 the decisions made by the person in ACP discussions such as in high-spending
38 areas.

39 However, the guideline committee was concerned about using evidence from the US about
40 end-of-life care as the system was very different from the UK. The guideline committee was
41 particularly concerned that in the US there was more pressure to deny life-prolonging
42 treatment and that thus effects of ACP could be different and lead to overestimations if
43 applied to the UK or England. In addition, most US studies referred to specific populations
44 such as people with severe dementia (e.g. Nicholas et al. 2014) or cancer (e.g. Wright et al.
45 2008; Zhang et al. 2009).

46 The guideline committee thus agreed to use evidence from the Australian study (Detering et
47 al. 2010) on effect of ACP on recorded CPR wishes. In their experience the Australian
48 system operated similar to the UK, and evidence on relative effects was thus considered
49 applicable to the UK and English context. Detering et al. (2010) evaluated whether or not

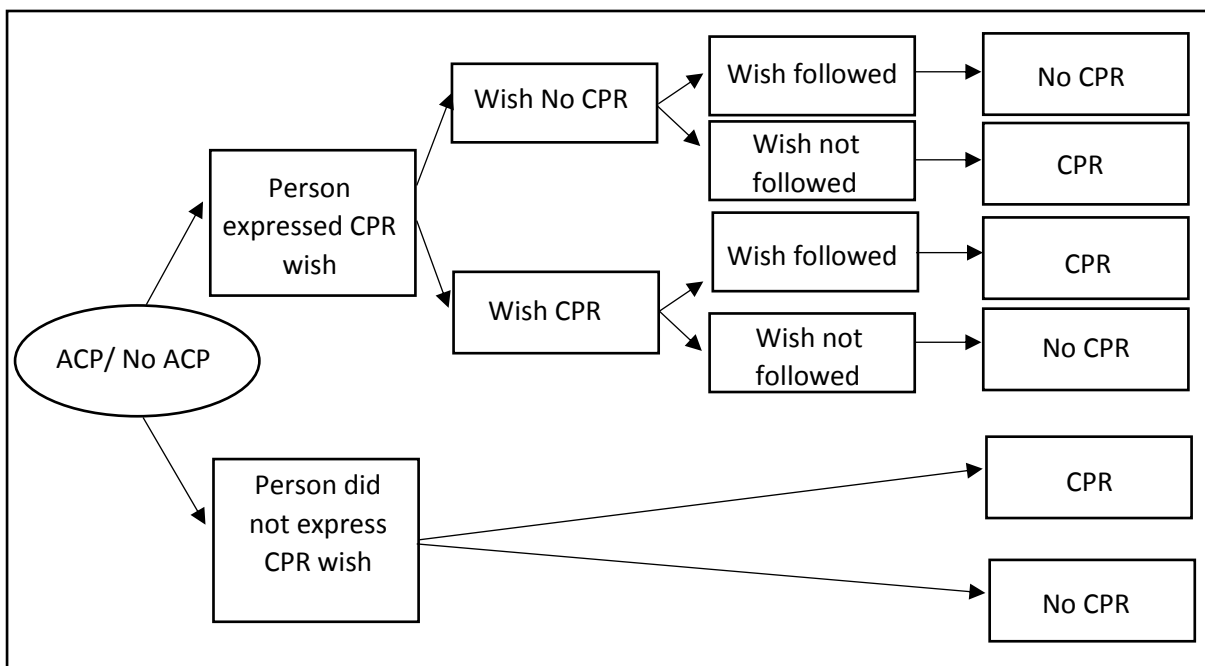
1 ACP changed the number of recorded CPR wishes and the nature of the wish (pro or
 2 against CPR) as well as whether the wish was followed. The study referred to people aged
 3 80 years or older admitted under internal medicine, cardiology, or respiratory medicine in a
 4 large university hospital in Melbourne. The study measured pre-existing wishes (before
 5 ACP) and showed that 38% (in both groups) wished DNACPR although only a proportion of
 6 those (17% in the intervention group and 21% in the control group) had completed a form.
 7 After participating in ACP, the proportion of people with recorded DNACPR wish increased
 8 from 38% to 42.4% in the intervention group (while in the control group the proportion was
 9 assumed to be the same as before since no further intervention had taken place). There was
 10 a significant reduction in the number of wishes known and followed (86% vs. 30%; $p < 0.001$).
 11 This was mainly due to a lower number of wishes being unknown in the intervention group
 12 (10% vs. 63%; $p < 0.001$); there were also differences in whether the person's wish had been
 13 followed (3% vs. 7%; $p = 0.51$) although this did not reach significance.

14 A decision tree was thus developed, with the aims to establish the number of CPRs carried
 15 out for people who were offered ACP versus those who were not (Graph 1).

16

17 Graph 1: Structure of decision tree used for modelling the cost consequences of ACP in
 18 relation to CPR

19



30

31 Data from this study informed the probabilities in the ACP group that ACP was offered to the
 32 person, that the person accepted the offer, that the person expressed wishes about CPR
 33 (verbally or in writing), that the wish was DNACPR and that the person's wishes were
 34 followed. Probabilities were also available for the control group regarding the person's
 35 wishes being DNACPR and wishes being respected. Some data on probabilities were
 36 available from a national source, the NCEPOD (2012), including the probability that the
 37 person's wish was recorded in standard care and that the person's DNACPR wish was not
 38 followed. Since those data referred to England and were of recent date, they were used for
 39 the standard care parameters where possible.

40 Neither Detering et al. (2010) nor the NCEPOD study (2012) measured number of cardiac
 41 arrests or CPR events and thus did not provide final evidence on size of reduction in CPR.

1 Thus additional evidence on cardiac arrests and CPR events was used to assess the
 2 potential impact of ACP on CPR events. Data on probabilities of cardiac arrests and CPR
 3 events in the last year of life could not be found directly from the literature and were thus
 4 derived from several data sources. The probability of an older person to have a cardiac
 5 arrest in their last year of life was estimated using data on in-hospital cardiac arrest per
 6 hospital admission (Sandroni et al. 2007; Nolan et al. 2007), which were multiplied by the
 7 number of hospital admissions in the last year of life (Bardsley et al. 2016), as well as the
 8 probability of out-of-hospital hospital cardiac arrest in the last year of life. The latter was
 9 calculated from data on number of cardiac arrests in 2006 by the National Out-of-Hospital
 10 Cardiac Arrest Project (Ambulance Service Association 2006), which were divided by
 11 population estimates from the Office of National Statistics for the same year.

12 The unit cost for CPR were derived from two sources in order to include a weighted average
 13 of those costs with and without admission to an intensive care unit (ICU). Petrie et al. (2015)
 14 provided an estimate of costs for people admitted to hospital with cardiac arrest and who
 15 were then referred to the ICU. Data from this study were from a single centre (London)
 16 retrospective review of in-hospital costs of patients admitted to the ICU and had the
 17 advantage that they evaluated the costs for people with cardiac arrest using the ICU rather
 18 than average unit costs of the ICU. The unit cost for inpatient cardiac arrest for people not
 19 using ICU was taken from the National Schedule of Reference Costs. The weighting of the
 20 two unit costs was done based on the probability that persons with cardiac arrest were
 21 admitted to an ICU, which was taken from the NCEPOD (2012) report (original source was
 22 Nolan et al. 2007).

23 Data on all parameters and values are shown in Table 4.

24 Table 4: Parameters, values, source and details for costing impact of ACP on CPR

Parameter	Mean or deterministic value	Range	Source and details
Intervention group (ACP)			
Probability that ACP offered to person	81%	72.9% to 89.1%	Detering et al. (2010), p3; range +/- 10%
Probability that person accepts ACP (=wishes recorded)	86%	77.4% to 94.6%	Detering et al. (2010), p3; range +/- 10%
Probability that recorded wishes also about CPR	82%	73.8% to 90.2%	Detering et al. (2010), p3; range +/- 10%
Probability that person's CPR-related wish is DNACPR	42.4%	38.16% to 46.63%	Detering et al. (2010), Table2; n=14 (verbal) and n=39 (written), divided by n=125 (=total no. in ACP group); range +/- 10%
Probability that person's wishes not followed	3%	2.7% to 3.3%	Detering et al. (2010), Table 3; range +/-10%
Standard care (no ACP)			
Probability that person's CPR wish recorded	22%	19.8% to 24.2%	NCEPOD, p.61; range +/-10%
Probability that person's CPR-	38%	34.3% to 41.8%	Detering et al. (2010); range +/-10%

related wish is DNACPR			
Probability that person's wish of DNACPR not followed	9.4%	8.5% to 10.36%	NCEPOD, p.61; range +/- 10%
Probability of person's CPR wish not followed	7%	6.3% to 7.7%	Detering et al. (2010); range +/- 10%
Probabilities of cardiac arrest and CPR in last year of life			
Probability of in-hospital cardiac arrest per hospital admission	0.16%	0.1% to 0.5%	Nolan et al. (2007); Sandroni et al (2007)
No. of hospital admissions in last year of life	2.28	0.11 to 4.45	Bardsley et al. (2016)
Probability that person has out-of-hospital arrest	0.524%	0.47% to 0.58%	Ambulance Service Association (2006): No. of out-of-hospital cardiac arrests of 57,345; ONS (2006); 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% to 48.2%	Ambulance Service Association (2006); refers to out-of-hospital arrest; 25,143 out of 57,345 received CPR
Unit costs (in 2015/16, £)			
Cost of CPR (without ICU)	2,484	848 to 3,572	National Schedule of Reference Costs Year 2015–16; refers to inpatient cardiac arrest
Cost of CPR (with ICU)	14,515	4,232 to 18,623	Petrie et al. (2015); Table 6 (ICU, all patients); total cost were divided by no. of people using the ICU (n=68) as reported on p.5; range reflects 25 th and 75 th centiles; adjustments were carried out to account for London Market Force Factor of 1.2417 (p3) i.e. amounts reported in study was divided by this to reflect national estimate; values were uprated from 2011/12 to 2015/16 prices
Cost of CPR with or without ICU	4,327	1,386 to 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, p61; original source was Nolan et al. 2007)

1 The mean cost linked to CPR in the ACP group was £37 per person (SD 31, 95% CI 30 to
2 33. Mean cost linked to CPR in the standard group was £41 per person (SD 34, 95% CI 32
3 to 36). The mean cost difference between the 2 groups was £2 per person (SD 4.2, 95% CI
4 3.9 to 4.4).

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7 5.2 Life-prolonging or sustaining treatment

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9 Life-prolonging treatment (LPT) – in the US literature sometimes referred to as aggressive
10 medical care – includes a range of treatments that take place around the time of death such
11 as: Chemotherapy for persons with cancer, assisted ventilation, and dialysis. There was
12 evidence that ACP was likely to influence the use life-prolonging treatment at the end of life,
13 and that people who knew more about LPT through ACP discussions were less likely to wish
14 such care because they had more realistic expectations of the benefits of LPT (e.g.
15 Prigerson 1992).

- 16 • The use of chemotherapy was reported in Zhang et al. (2009) and showed a reduced
17 use of people in the intervention group although this did not reach significance
18 ($p>0.1$).
- 19 • Kirchhoff et al. (2012) reported a significant lower use of dialysis in the intervention
20 group (37.7% vs. 17%) although they did not report confidence intervals or p-values.
21 Patients belonged to a specific population, which had congestive heart failure or end-
22 stage renal disease. No other studies were identified to confirm the relationship and
23 the researchers suggested that further research is needed.
- 24 • Assisted ventilation was also a primary outcome in studies that evaluated ACP
25 regarding LPT (Wright et al. 2008; Zhang et al. 2009). Studies showed significantly
26 lower rates of assisted ventilation in the ACP group (Wright et al. 2008: 1.6% vs.
27 11%; adjusted odds ratio 0.26, 95% CI 0.08 to 0.83, $p<0.05$; Zhang et al. 2009: 1.3%
28 vs. 14.3% adjusted odds ratio 0.03, 95% CI 0.002 to 0.3, $p<0.05$).

29 Assisted ventilation was also one of the more common forms of LPTs. The End of Life Care
30 Audit 2016 (p32) found that 11% of persons dying in hospital had assisted ventilation around
31 the time of death (whereas only 1.7% had dialysis). The Audit also showed that only 23% of
32 those had a documented discussion about continuing or stopping ventilation. In this analysis,
33 only assisted ventilation was thus included as LPT.

34 Following the same approach used for CPR, a model was developed to examine the
35 potential reduction in LPT (in form of assisted ventilation) for people who were offered ACP.
36 The structure of the model was the same as for CPR (see Graph 2). As before, the evidence
37 from US studies (Wright et al. 2008; Zhang et al. 2009) was not used to inform the model as
38 the guideline committee thought that effect sizes were likely to be different in a UK context.

39

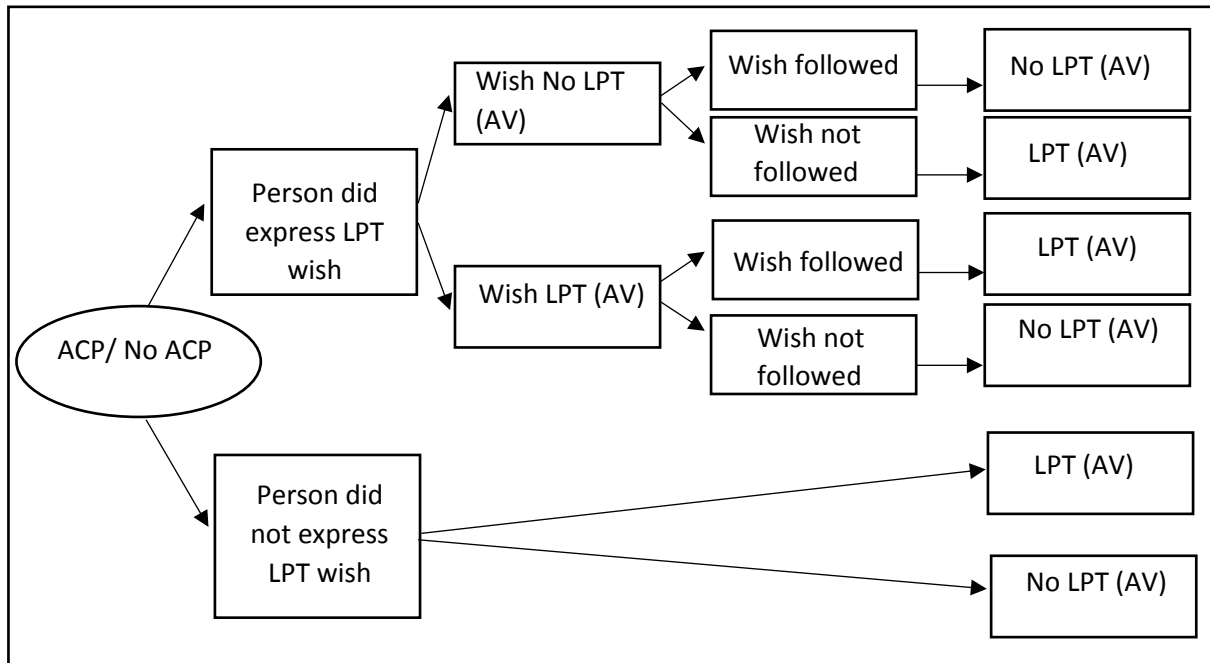
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Graph 2: Structure of decision tree used for modelling the cost consequences of ACP in relation to LPT



Thus, as for the analysis for CPR, data from Detering et al. (2010) informed the probabilities in the ACP group that ACP was offered to the person, that the person accepted the offer, that the person expressed wishes about LPT (verbally or in writing), that the wish was LPT and that the person's wishes were followed. Probabilities were also available for the control group regarding the person's wishes being LPT and wishes being respected. Data on the probability that a person's LPT wishes (regarding assisted ventilation) were recorded were available from the End of Life Care Audit (EOLCA 2016), and those were included in the analysis to increase the relevance of the analysis to the English context.

Probabilities that a person would receive assisted ventilation in their last year of life was derived from the probability that a person would die in hospital (ONS 2016) and the probability that the person dying in hospital would use assisted ventilation (EOLCA 2016).

No estimates of the incremental costs of ventilation (as a distinct component of hospital services) could be identified from UK sources. However, data from the EOLCA (2016) showed that 70.33% of people received assisted ventilation in the ICU and it was assumed the admission to the ICU was made to provide assisted ventilation. Costs for ICU were thus assigned to assisted ventilation by multiplying the probability of admission to the ICU with the unit cost of ICU. The unit cost of ICU were taken from Petrie et al. (2015) and referred to people with cardiac arrest (which is one reason for the need to provide assisted ventilation).

All parameters and values used for the modelling are shown in Table 5.

1 Table 5: Parameters, values, sources and details for modelling cost impact of ACP on LPT

Parameter	Mean or deterministic value	Range	Source and details
Intervention group (ACP)			
Probability that ACP offered to person	81%	72.9% to 89.1%	Detering et al. (2010), p3; range +/- 10%
Probability that person accepts ACP (=wishes recorded)	86%	77.4% to 94.6%	Detering et al. (2010), p3; range +/- 10%
Probability that recorded wishes also about LPT	75%	67.5% to 82.5%	Detering et al. (2010), p3; range +/- 10%
Probability that person's LPT-related wish is No LPT	31.2%	28.1% to 34.3%	Detering et al. (2010), Table2; n=10 (verbal) and n=29 (written), divided by n=125 (=total no. in ACP group); range +/- 10%
Probability that person's wishes not followed	3%	2.7% to 3.3%	Detering et al. (2010), Table 3; range +/-10%
Standard care (no ACP)			
Probability that person's LPT wish recorded	23%	20.7% to 25.3%	EOLCA; refers to documented discussion with person about continuing or stopping ventilation
Probability that person's LPT wish is No LPT	20%	18% to 22%	Detering et al. (2010); range +/- 10%
Probability that person's wish of No LPT not followed	9.4%	8.5% to 10.36%	NCEPOD, p.61; range +/- 10%
Probability of person's wish not followed	7%	6.3% to 7.7%	Detering et al. (2010); range +/- 10%
Probabilities of assisted ventilation in last year of life and that assisted ventilation takes place in ICU			
Probability of death in hospital	47%	42.3% to 51.7%	ONS (2016a)
Assisted ventilation for people dying in hospital	11%	9.9% to 12.1%	End of Life Care Audit (EOLCA 2016, p32); range +/- 10%
Probability that assisted ventilation takes place in the ICU	70.33%	63.3% to 77.4%	End of Life Care Audit (EOLCA 2016, p33); range +/- 10%
Unit costs (in 2015/16, £)			
Cost of ICU	14,515	4,232 to 18,623	Petrie et al. (2015); Table 6 (ICU, all patients); total cost were 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 (p3) i.e. amounts reported were divided by this; uprated from 2011/12 to 2015/16 prices

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The mean cost of assisted ventilation in the ACP group was £436 per person (SD 225, 95%CI 212 to 238) and £501 (SD 225, 95% CI 212 to 238) in the standard care group. The mean difference was £65 (SD 37, 95% CI 35 to 40).

5.3 Place of death

Evidence from the UK suggests that ACP can influence the place in which people die, i.e. people are more likely to die in their preferred place of death, which is most commonly their usual place of residence, typically their own home or care home (e.g. Gomes et al. 2011, 2013; NatCen 2013). The influence of ACP on place of death might be explained in two ways: 1) the preferred place of death is explicitly discussed in ACP discussions (e.g. Dixon et al. (2016); 2) decisions about CPR and LPT might influence the place of death (Brinkman-Stoppelenburg et al. 2014); for example, the ambulance might not take the person to the hospital if the person's wish was not to receive CPR, and instead the person might die at their usual place of residence. The place of death is known to determine costs at the end of life so that there are potentially important economic consequences linked to ACP, which would need to be considered in the economic analysis.

The following evidence on the impact of ACP on place of death was identified:

- A recent systematic review of ACP (Brinkman-Stoppelenburg et al. 2014) identified 6 studies that measured place of death as an outcome; 3 studies reported a decrease in hospital deaths, 1 study reported a decrease in ICU deaths and 2 studies reported an increase in death at home; 4 of the studies were from the US, and only 1 from England (Abel et al. 2013). Since then, according to Dixon et al. (2016), 2 more US studies have been published (Bischoff et al. 2013; Nicholas et al. 2014), which both identified a lower risk of hospital death in people who were offered ACP.
- Detering et al. (2010) also found that people who were offered ACP were less likely to die in the ICU (0% vs. 15%; $p < 0.05$); no other significant impact of ACP on place of death was found, also findings showed higher rates of persons dying at home/in a care home and in a hospice (24% vs. 11%; $p = 0.2$); while). In this Australian study place of death was only measured in a sub population of people who died during the study period ($n = 56$) so that the sample was arguably too small to pick up all changes.
- The English study by Abel et al. (2013) found that for people in hospice mean hospital costs in the last year of life were much lower when people died in their place of residence rather than in hospital (£7,730 vs. £11,299; $p < 0.001$); unfortunately, the study did not present findings in a way which established the impact of ACP on the costs of place of death directly. However, the study found that the proportion of people with cancer who died in hospital in the ACP versus standard care group was 10% versus 26%; the study did not report p-values or confidence intervals. In addition, the study referred to a hospice population and only a small proportion of people access this kind of service towards end of life so findings could not be applied to the general population of older people at the end of life; in particular people who access hospice care are much more likely to not die in hospital compared with the general population (for example, nationally 47% of people above 65 years die in

1 hospital, which is much above the proportions identified in the standard care group of
2 26%).

- 3
4 • Another study relevant to the English context was identified, which was based on a
5 large postal survey of a random sample of UK general practices (Hughes et al.
6 2009). The study found that practices using ACP were 2.5 more likely to have home
7 death rates for patients with cancer of over 60%. However, data were only collected
8 at the practice and not individual level, so that important factors that were likely to
9 have influenced the relationship at an individual level could not be controlled.
- 10
11 • Dixon et al. (2016) carried out secondary analysis of data from the National Survey of
12 Bereaved People 2013 in England and found that people who received ACP were
13 more likely to die at home (care home) than in hospital (odds ratio 6.25, 99% CI, 5.56
14 to 7.14 and odds ratio 2.7, 99% CI, 2.33 to 3.13). While the study had some
15 limitations related to the study design (it was not an evaluation of ACP and whether
16 ACP had taken place was based on a single indicator of whether a discussion about
17 end of life was recorded), it presents important evidence based on a statistically well
18 powered and nationally representative data set, which controlled for many individual
19 level factors, which had been found in previous studies to influence the relationship
20 between ACO and place of death such as cancer diagnosis, living in a more affluent
21 area and having a spouse or partner.

22
23 For the analysis, the potential impact of ACP on place of death was modelled based on
24 findings from Dixon et al. (2016), which was the only England-based study, which measured
25 the impact of ACP on place of death based on a nationally representative sample using
26 individual-level data. A complication was that the study provided odds ratios that compared
27 effects of ACP by looking at 2 places of death in relation, i.e. death in hospital versus death
28 at home and death in hospital versus death in a care home (rather than death at home or a
29 care home versus death elsewhere). However, the relative risk of death in hospital versus
30 death elsewhere was reported (in the discussion section). Some adjustments needed to be
31 made because of the way data were analysed: First, hospice needed to be included as a
32 potential place of death. Although only very few people die in hospice this is a costly service
33 and some studies – like the one by Detering et al. (2010) found that ACP might increase the
34 probability for a person to die in hospice. So it was important to include this as an outcome
35 to not overestimate potential cost savings. Second, probabilities in the ACP group that were
36 derived from the 2 odds ratios needed to be adjusted so that the sum of probabilities
37 between different places of death added up to one. This step is explained later on.

38 For the analysis, 4 different places of death were considered as outcomes affected by ACP:
39 Death in hospital, death at home, death in a care home and death in a hospice. Probabilities
40 in standard care were estimated based on national statistics on the place of occurrence of
41 deaths in the population of people 65 years and above in England and Wales (ONS 2016).
42 The relative risk of death in hospital versus elsewhere in ACP versus standard care was
43 reported in and could be thus taken directly from Dixon et al. (2016). Relative risks (RR) for
44 dying in home or in care home rather than in hospital between the ACP versus standard care
45 group were derived from odds ratios (OR) provided by Dixon et al. (2016) using a standard
46 formula for conversion (with p_0 presenting the probability in the standard care group).

$$47 \quad RR = OR / (1 - p_0 + p_0 \times OR)$$

1 In addition, data on the relative risk of dying in hospice care were taken from Detering et al.
2 (2010). Next, probabilities for people in the ACP group to die in different places were
3 calculated based on probabilities in standard care and relative risks. As mentioned, an
4 adjustment had to be made in order to include the odds ratios from Dixon et al. (2016), which
5 referred to relative effects between 2 places of death.

6 First, the probability (p) of someone not dying in hospital was derived as follows:

$$7 \quad p(\text{death not in hospital}) = 1 - p(\text{death in hospital}).$$

8

9 From this the probability that a person was dying at home or in a care home was derived:

$$10 \quad p(\text{death in care home or home}) = p(\text{death not in hospital}) - p(\text{death in hospice}).$$

11

12 Next, the probability of a person dying at home was derived:

$$13 \quad p(\text{death at home}) = p(\text{death at home or care home}) \times [p(\text{death at home}) / (p(\text{death at home}) + p(\text{death in care home}))].$$

14

15

16 Finally, the probability of a person dying in a care home was calculated as follows:

$$17 \quad p(\text{death in care home}) = p(\text{death in care home or home}) - p(\text{death at home}).$$

18

19 Costs were assigned to the probabilities of person dying in different places in both groups:
20 ACP and standard care. The mean cost of the final episode in hospital ending in death was
21 taken from a published national source, the Quality Improvement Programme, and referred
22 to a national tariff published by the National End of Life Care Programme (NEOLCP 2012).
23 Ranges were taken from Georghiou and Bardsley (2014) and NICE (2011). Costing deaths
24 in other places than hospital required some assumptions about the period on which costs
25 should be based. Since the costs of those dying in hospital referred to the last episode
26 ending in death it was considered most appropriate to use this length of time to calculate the
27 costs of dying in other places. The average number of days during the last episode of care in
28 hospital ending in death was found to be 12.9 days in a recent national source (Public Health
29 England 2013, What we know now, p16). So this estimate was taken for the calculations of
30 unit costs of dying in different places.

31 There was a particular challenge in valuing community provision (for people who die at
32 home), which has been found to differ substantially across places depending on local
33 commissioning arrangements. As a result, the additional community health and social care
34 costs of a person who is not admitted to hospital around the time of death will be different for
35 different localities. Estimates on the costs of dying at home from the literature were based on
36 different lengths of episodes of care (e.g. last months of life, 2 weeks of life, last week or life
37 or just last days of life); some values were from unpublished sources and it was not made
38 transparent to which period cost estimates referred to and which assumptions they had
39 applied. So, some additional steps were taken. First, the costs of care per day required in
40 the community for someone dying at home were estimated. This was done based on
41 estimates of resource inputs and costs provided in a report by Marie Curie (Marie Curie
42 Cancer Care – Understanding the cost of end of life care in different settings). Values were

1 either updated to current price levels or updated with more recent estimates from PSSRU
 2 Unit Cost Book (PSSRU 2016). Table 6 shows the resource inputs, unit costs, source and
 3 details that informed the calculation. The average cost per day was £143.5 and values
 4 ranged from £78.7 to £204.9. The cost per day was then multiplied with the average length
 5 of stay for people who die in hospital to derive the costs of care required in the community as
 6 a result of a person not being admitted to hospital; the resulting estimates were £1,850.8 and
 7 ranged from £1,015.4 to £2,645.

8 The costs of other places of death (care home and hospice) were calculated by multiplying
 9 unit costs from PSSRU Unit Costs for Health and Social Care (2016), with the average
 10 length of stay of 12.9 days for someone admitted to hospital for their final episode ending in
 11 death.

12

13 Table 6: Cost of community care package that patients receive at the end of life (per day),
 14 based on information by Marie Curie report 'Understanding the costs of end of life'

Resource input	Mean cost (per day), in £, 2015/16 prices	Range (If not provided: +/- 10%)	Source and details
NHS district nurse (visit every 3 rd day)	13.9	12.6 to 15.4	Based on visit every 3 rd day; £91/ hour, refers to district nurse (adults), face-to-face contact, in 2010/11 prices
Community nurse	71.3	35.7 to 106.9	Based on £465/ week in 2010/11 prices
Social care (for people at home)	29.3	14.6 to 43.9	Based on Bardsley et al. (2010), refers to average use of social care in the last year of life; only about 30% will require social care and costs much higher towards end of life; so that this is only rough estimate
Community specialist palliative care provided by nurse	13.1	7.7 to 15.3	Based on 1 hour/ week for community specialist palliative nurse; 92/hr (£54 to £107); face-to-face contact
Hospital or hospice palliative care outpatient services	15.8	8.1 to 23.4	PSSRU (2016), p95 refers to medical and non-medical specialist palliative care attendance, based on 1 appointment per week; range from £57 to £164; midpoint taken as mean

15

16 Table 7: Parameters, values, sources and details for costing impact of ACP on place of
 17 death

Parameter	Mean or deterministic value	Range	Source and details
Standard care			
Probability of dying in hospital	47.7%	42.9% to 50.6%	ONS (2016a); Table 8, deaths: place of occurrence and sex by underlying cause and age group; calculated for 65yrs+

Probability of dying at home	21.6%	19.4% to 23.8%	As above
Probability of dying in care home	24.8%	22.3% to 27.3%	As above
Probability of dying in hospice	0.5%	0.45% to 0.55%	As above
Relative risk of dying in different settings, ACP vs. standard care			
Relative risk of dying in hospital	0.46	0.42 to 0.51	Dixon et al. (2016); p8; range +/- 10%
Relative risk of dying at home (rather than hospital)	2.93	2.90 to 2.94	Dixon et al. (2016); derived from odds ratio (and range) with conversion formula: $RR=OR/(1-p_0 + p_0 \times OR)$
Relative risk of dying in care home (rather than hospital)	1.68	1.63 to 1.71	Dixon et al. (2016); derived from odds ratio (and range) with conversion formula: $RR=OR/(1-p_0 + p_0 \times OR)$
Relative risk of dying in hospice	1.52	0.76 to 1.52	Detering et al. (2010)
ACP			
Probability of dying at home rather than hospital	63.3%	56.5% to 70.1%	Derived from parameters above: probability of dying at home in standard care multiplied by relative risk of dying at home, ACP vs. standard care
Probability of dying in hospital	21.9%	17.8% to 26.5%	Derived from parameters above: probability of dying in hospital in standard care multiplied by relative risk of dying in hospital, ACP vs. standard care
Probability of dying in care home rather than hospital	47.1%	40.1% to 54%	Derived from parameters above: probability of dying in hospital in standard care multiplied by relative risk of dying in hospital, ACP vs. standard care
Probability of dying in hospice	0.77%	0.34% to 0.84%	Derived from parameters above: probability of dying in hospital in standard care multiplied by relative risk of dying in hospital, ACP vs. standard care
Unit costs (in 2015/16 £)			
Death at home	1,862	1,021 to 2,661	Own calculation; see Table
Death in hospital	3,000	2,506 to 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 to 1,554	PSSRU (2016), p205; Refers to cost of residential care or nursing home for people 65yrs +; for 12.9 days
Death in hospice	5,121	3,728 to 6,966	PSSRU (2016), refers to inpatient specialist palliative care for adults per day; multiplied by 12.9 days

1 The mean cost of last days of death (linked to the place of death) was £2,416 per person in
2 the ACP group (SD 236, 95% CI 2,414 to 2,444 to 257) and £2,508 in the standard care
3 group (SD 250, 95% CI 235 to 266).

5 6. Impact on health-related quality of life

7 ACP has not only been linked to cost consequences but also to changes in health-related
8 quality of life for persons dying as well as their carers (e.g. Dixon et al. 2015). Persons dying
9 and their carers might experience a different quality of death depending on whether or not
10 they received ACP.

- 11 • A concern expressed by some is that ACP might lead to an increase in stress and
12 worries since people are asked to think and talk about their death. However, this has
13 not been confirmed in evaluations and most studies report either no difference or a
14 positive impact on satisfaction and on being worried (Wright et al. 2008; Zhang et al.
15 2009; Brinkman-Stoppelenburg et al. 2014). The British Social Attitudes Survey
16 found that 70% of the public are comfortable talking about death (NatCen 2013).
17
- 18 • It is possible that people who as a result of ACP achieve their preferred place of
19 death, experience a different quality of life associated with place of death. The
20 National Survey of the Bereaved (VOICES) found that 52% of people dying at home
21 have pain relief only partially or not all met compared to 32% in hospital, 26% in a
22 care home, and 13% in hospice (ONS 2016b). However, there is no evidence of a
23 direct link between ACP and whether or not a person dies with controlled pain; the
24 relationship is complex as it depends on the quality of care provided in the person's
25 home. ACP might also have an influence on the quality of end-of-life care, including
26 pain management. It is also possible that person have weighted up the cons and
27 pros of dying at home and the choice to die at home might reflect a greater
28 acceptance of pain.
29
- 30 • Wright et al. (2008) found that carers reported that the person dying had a higher
31 quality of death if ACP was provided (adjusted odds ratio 1.17; 95% CI 1.05 to 1.29;
32 $p < 0.005$). This was explained by people in the ACP group being significantly less
33 likely to get LPT. Persons who did not receive LPT had a significantly higher mean
34 QoL score compared to persons who received several LPTs (6.4 versus 4.6; $p < 0.05$).
35
- 36 • Zhang et al. (2009) measured person's quality of life by asking carers and nurses
37 and found that whereas people who had participated in ACP were reported to have
38 less physical distress than those who had not (3.5 vs. 4.5, $p < 0.05$), the 2 groups did
39 not differ in psychological distress, quality of death or survival. Similarly to Wright et
40 al. (2008), they found that higher medical costs for more LPTs were associated with
41 quality of death ($p < 0.01$).

42 It is important to note that the majority of studies measure quality of life of the person by
43 asking carers or professionals. The limitations of relying on carers as a proxy for quality of
44 life have been discussed in the literature (e.g. Zhang et al. 2009). More generally, the
45 challenges of valuing quality of life towards end of life have been discussed in the literature
46 (Albers et al. 2010) and knowledge gaps are recognised and valid quality of life or quality of
47 care measures are being developed and tested (NEOLCIN 2015). However, for the purpose

1 of this analysis it was not considered feasible to value the impact of ACP on the quality of life
2 of people at the end of life.

3 There is some more robust evidence on the impact of ACP on carers.

- 4 • In particular, less LPT has been linked to better overall physical and mental health of
5 the carer (Curtis 2008; Casarett et al. 2006, SUPPORT study). Findings from the
6 study by Wright et al. (2008) showed that carers' quality of life was lower at 6.5
7 months after the person had died if the person had received LPT (adjusted odds ratio
8 0.57; 95% CI 0.29 to 1.11; p=0.1). They were also more likely to report regret
9 (p<0.05) and were at higher risk of developing a major depressive disorder (adjusted
10 odds ratio 3.37; 95% CI 1.12 to 10.13; p<0.05). One older US study (Tilden et al.
11 2004) found no significant impact on caregiver strain.
12
- 13 • Detering et al. (2010) evaluated carers' quality of life using a standardised outcomes
14 measure, the Hospital Anxiety and Depression Scale (HADS), which they applied for
15 the subsample of persons who died before discharge (n=56). They found lower
16 median scores in both, depression and anxiety, for carers of persons who had been
17 offered ACP (depression median score 0 vs. 5 with p<0.001; anxiety median score 0
18 vs. 3 with p<0.05). In terms of the cut-off points for anxiety and depression (score
19 >8), which defined the likelihood of a disorder, the study found that: probabilities to
20 score above the cut-off point were 0 for carers in the ACP group (for both depression
21 and anxiety) compared with 30% for depression (p<0.005) and 19% for anxiety
22 (p<0.05) in the standard care group.
23

24 Generally, there has been little conflicting evidence so that findings of a positive effect of
25 ACP on carers' quality of life appeared to be consistent. As before, the guideline committee
26 agreed to not use evidence from the US and information was instead used from Detering et
27 al. (2010). This included probabilities of developing depression or anxiety in the ACP and
28 standard care groups. It is important to note that in regards to applying a range to those
29 values for the purpose of PSA an exception was made for the prevalence of
30 anxiety/depression in the intervention group. The value was according to the Detering study
31 0; this was considered as potentially too low; the impact of using higher prevalence values
32 were considered in one-way sensitivity analysis. Data from Detering et al. (2010) presented
33 probabilities for depression or anxiety separately. Since there is a potentially strong overlap
34 between the 2 conditions, a combined estimate was derived for the probability of a person to
35 have depression and/or anxiety. This was done by taking a minimum value, which referred to
36 probability of depression if a 100% overlap with anxiety problems was assumed; and a
37 maximum value, which referred to the probability of either depression or anxiety if 0%
38 overlap between the 2 conditions was assumed. As a mean the midpoint between minimum
39 and maximum values was taken. Next, a time period was determined during which the carer
40 experienced depression and/ or anxiety. The study by Detering et al. (2010) measured
41 carers' outcomes only at one time, which reflected a maximum 6 months follow up. The 6
42 months was taken as a maximum period over which the carer might have experienced
43 depression and/or anxiety. An estimate of 2 months was taken as a minimum value. It is
44 possible that some people experience a shorter episode of anxiety or depression and it was
45 also possible that people might experience depression or anxiety for longer than 6 months.
46 Health utility values were assigned to the health states and taken from Roberts et al. (2014).
47 Roberts et al. (2014) used data from the Adult Psychiatry Morbidity Surveys of a
48 representative sample of the general population in England. Health state utility values were
49 measured by the SF-6D and EQ-5D indices and included those for anxiety, depression and

1 mixed anxiety and depression. Both indices are valid tools for measuring health utilities and
 2 it has been found that they strongly correlate with the HADS (e.g. Jutte et al. 2015). In
 3 Roberts et al. (2014), the SF-6D was derived from individual responses to the SF-12 and the
 4 EQ-5D was derived by mapping from SF-12 items using a response approach mapping.
 5 Since the study provided a wide range of relevant estimates for different conditions
 6 (depression, anxiety, combined) and measured via different tools (EQ-5D and SF-6D), a
 7 weighted health utility was calculated from all health utility scores for depression, anxiety and
 8 mixed anxiety and depression, measured by the SF-6D and EQ-5D. **Note that it was**
 9 **agreed with NICE that for the final report only EQ-5D values would be considered in**
 10 **the analysis reflecting NICE preference for this measure of health-related quality of**
 11 **life. Whilst this will require updating of the findings it is unlikely to change them**
 12 **substantially or to affect the conclusions.**

13 All parameters and values that informed the calculations of QALYs are shown in Table 8.
 14

15 Table 8: Parameters, values, sources and details for valuing impact of ACP on health-related
 16 quality of life

Parameter	Mean or deterministic value	Range	Source and details
Probability of anxiety or depression, ACP group	0	/	Detering et al. (2010)
Probability of anxiety or depression, standard care	0.4	0.3 to 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 to 0.5	Assumptions; maximum time was informed by Detering et al. (2010), which used a follow up of 6 months
Health utilities			
Depression (measured with EQ-5D)	0.537	SD 0.311	Roberts et al. (2014); refers to representative sample of the general adult population in England
Depression (measured with SF-6D)	0.551	SD 0.105	As above
Anxiety (measured with EQ-5D)	0.643	SD 0.288	As above
Anxiety (measured with SF-6D)	0.626	SD 0.141	As above
Mixed anxiety and depression	0.681	SD 0.258	As above

(measured with EQ-5D)			
Mixed anxiety and depression (measured with SF-6D)	0.657	SD 0.132	As above
Weighted anxiety, depression, and anxiety and depression combined	0.612	0.410 to 0.822	Calculated from above; presents an average across all utility scores
No mental health problems (measured with EQ-5D)	0.827	SD 0.114	Roberts et al. (2014); refers to representative sample of the general adult population in England
No mental health problems (measured with SF-6D)	0.842	SD 0.17	As above
No mental health problems, combined	0.835	0.693 to 0.977	Calculated as an average from the 2 utility scores for no mental health problems: EQ-5D and SF-6D

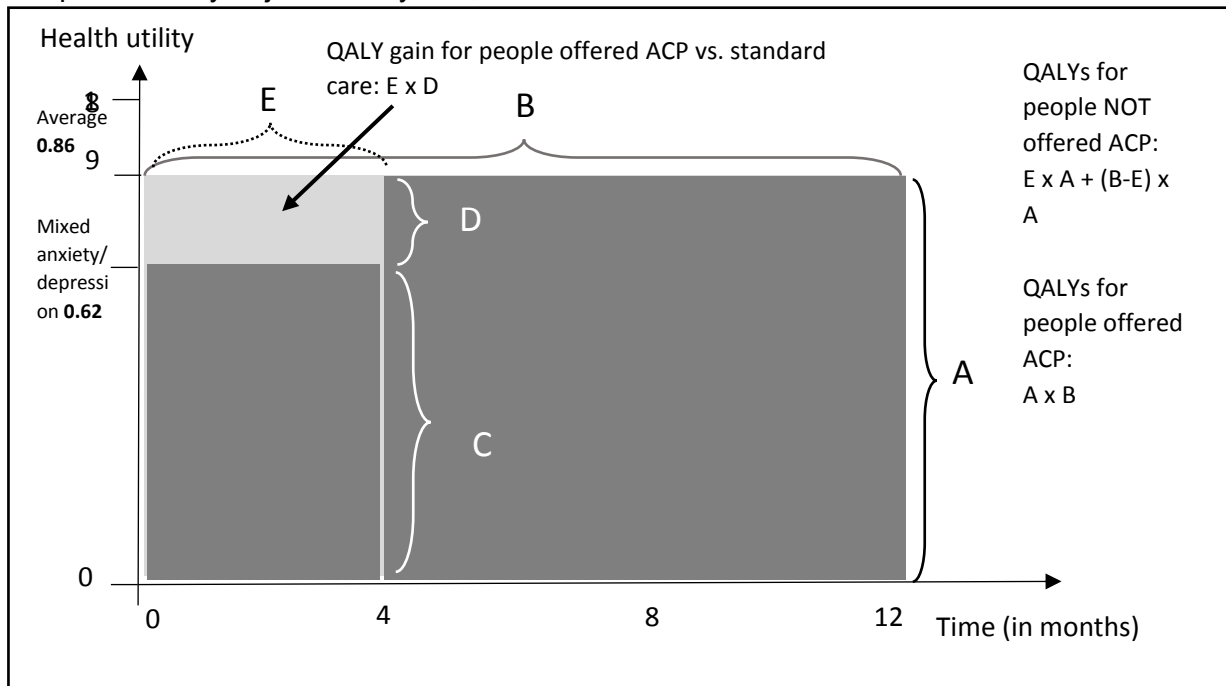
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2 Mean QALY was 0.83 in the ACP group (SD 0.07, 95% CI 0.83 to 0.84) and 0.8 in the
 3 standard care group (SD 0.06, 95% CI 0.79 to 0.8). The mean difference in QALYs was 0.04
 4 (SD 0.02, 95% CI 0.03 to 0.04).

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6 Graph 3: Quality-adjusted life years, ACP versus standard care

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7. Results of the incremental cost-effectiveness ratio (ICER)

The aim was to present results in form of the ICER for this analysis, and the uncertainty surrounding it. The calculation of the ICER was important as it allowed a conclusion about likely cost-effectiveness of ACP. This is based on the decision rule that if the ICER is below the thresholds of £20,000 to £30,000 per QALY, the intervention can be considered cost-effective. The ICER is calculated by dividing the mean difference in total costs between ACP versus standard care by the mean difference in QALYs between the 2 groups.

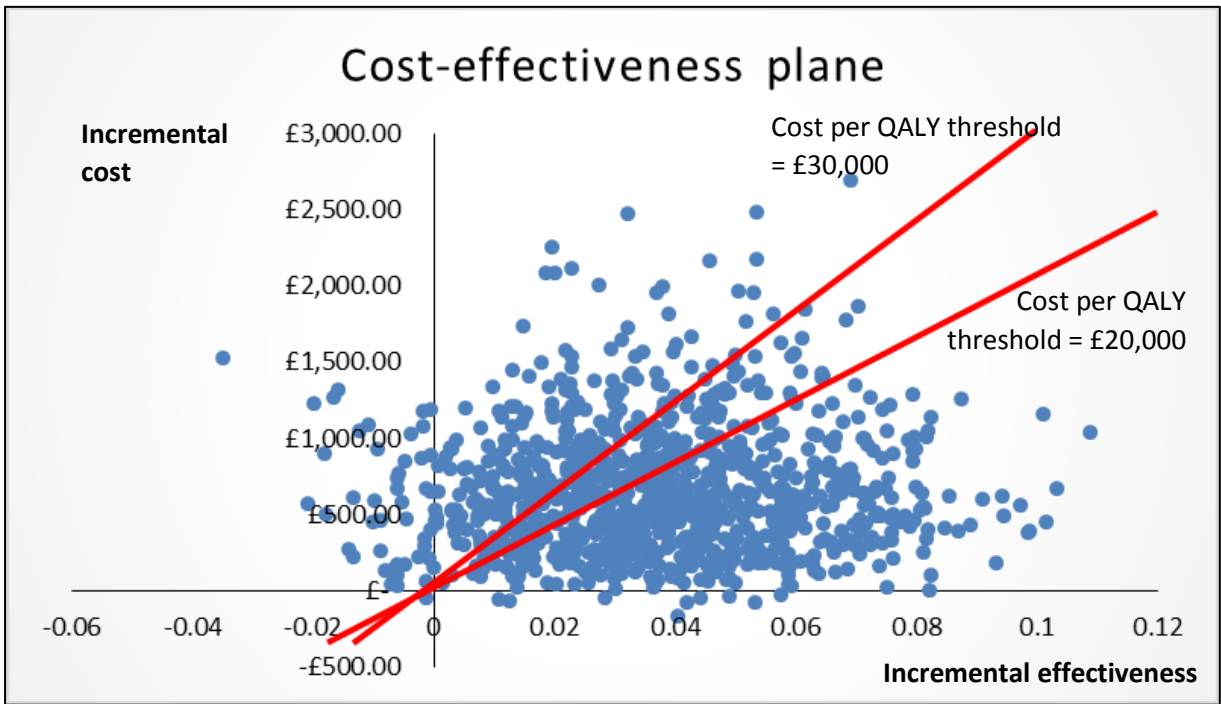
First, total costs were calculated for the ACP and standard care group by aggregating the costs calculated in sections 3 and 4. Costs in the ACP group were calculated by aggregating the cost of ACP with the cost consequences linked to cardiopulmonary resuscitation, LPT (in form of assisted ventilation) and place of death. Costs in the standard care group were calculated by aggregating cost consequences of those 3 outcomes. Mean total costs in the ACP group were £3,748 (SD 539, 95% CI 502 to 572). Mean total costs in the standard care group were £3,072 (SD 354, 95% CI 332 to 376). The mean difference in total costs between the 2 groups was £677 (SD 430, 95% CI 403 to 457).

Next, the ICER was derived by dividing the mean difference in total cost by the mean difference in QALYs (section 4). The mean ICER for the base case for this throw of data was then £16,925. Confidence limits on ICER do not give the information needed when there is a (non-negligible) chance that the ICER value could be negative. During the 1,000 Monte Carlo simulations, the ICER turned a few times negative when the total mean costs linked to ACP were greater than the total mean costs of standard care while there was also a QALY loss (i.e. mean QALYs were smaller in the ACP group compared with the standard care group). The uncertainty surrounding the ICER was thus presented differently, in form of a Cost-effectiveness plane and curve.

On the cost-effectiveness plane shown in Graph 4, different combinations of incremental costs and incremental effects are presented in form of a cloud of points corresponding to different iterations of the probabilistic sensitivity analysis. Each combination (dot) represents one of altogether 1,000 Monte Carlo simulations and thus reflects the distribution of values for each parameter. The 2 red lines represent cost-effective points for thresholds of £20,000 and £30,000. All dots on or under those lines would present cost-effective combinations of incremental costs and effects. That means, the greater the number of dots under those lines (rather than above) the greater the probability that ACP is cost-effective. The cloud of points shown here shows that a similar number of dots above and under the red line that symbolises the threshold of £20,000. If looking at the red line that symbolises a threshold of £30,000, more dots lie under than above the line thus signalling that ACP is cost-effective if this higher cost per QALY threshold is applied.

The cost-effectiveness acceptability curve is shown in Graph 5 and summarises the impact of uncertainty on the ICER in relation to a range of values of the cost-effectiveness thresholds. In the graph, a range of cost-effectiveness thresholds are plotted on the horizontal axis against the probability that ACP is cost-effective at each of these thresholds on the vertical axis. For example, at a threshold of £20,000 per QALY the probability that ACP is cost-effective is above 55% and at a threshold of £30,000 per QALY the probability that ACP is cost-effective is above 70%.

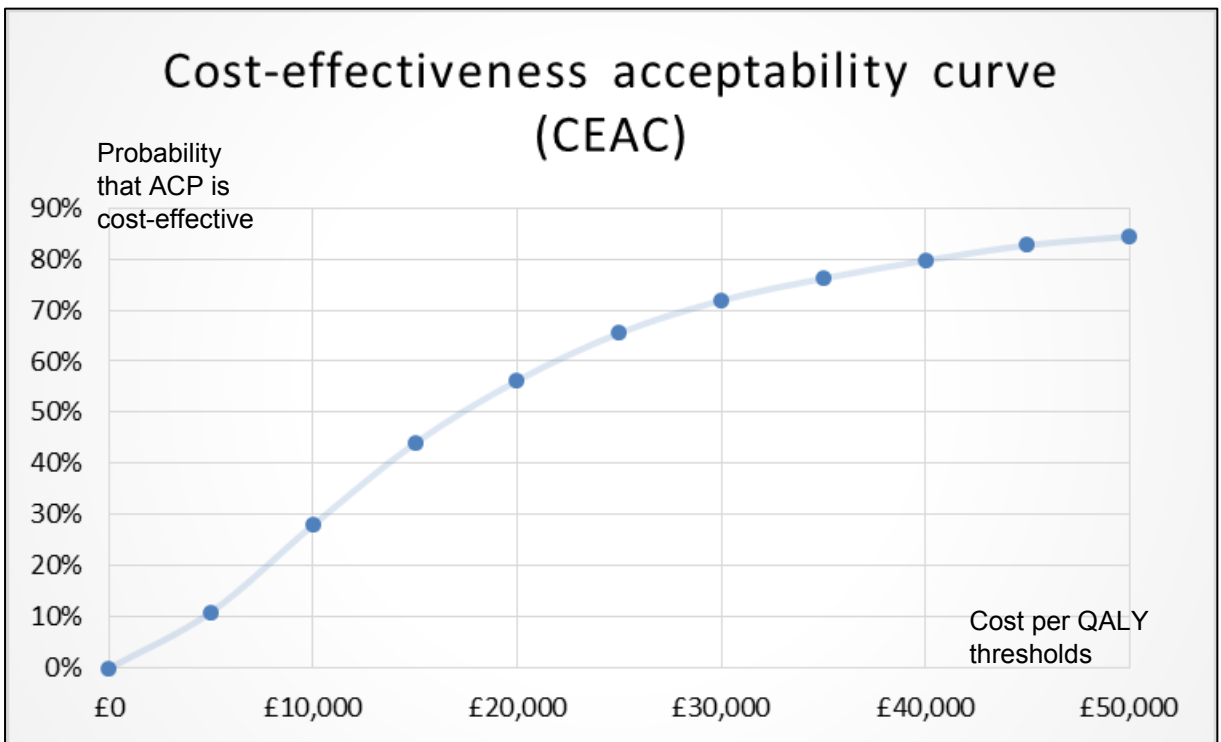
1 Graph 4: Cost-effectiveness plane showing results, base case



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4 Graph 5: Cost-effectiveness acceptability curve showing results, base case



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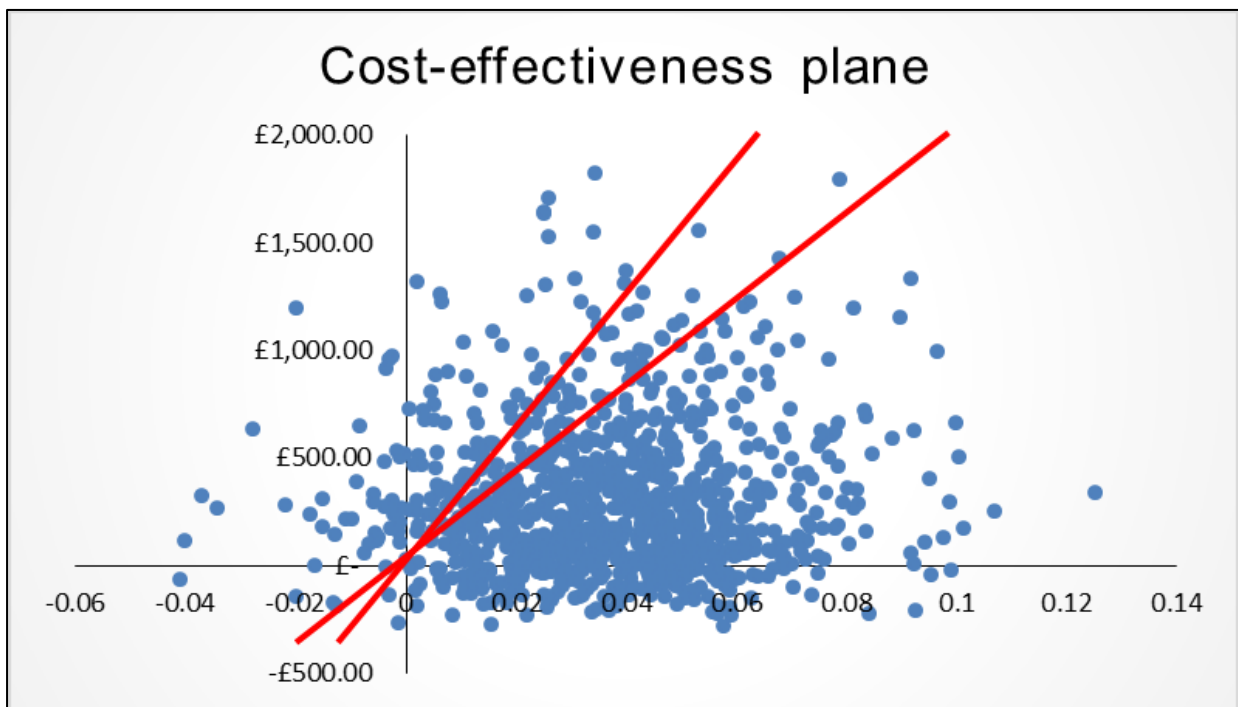
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8. Findings from one-way and two-ways sensitivity analysis

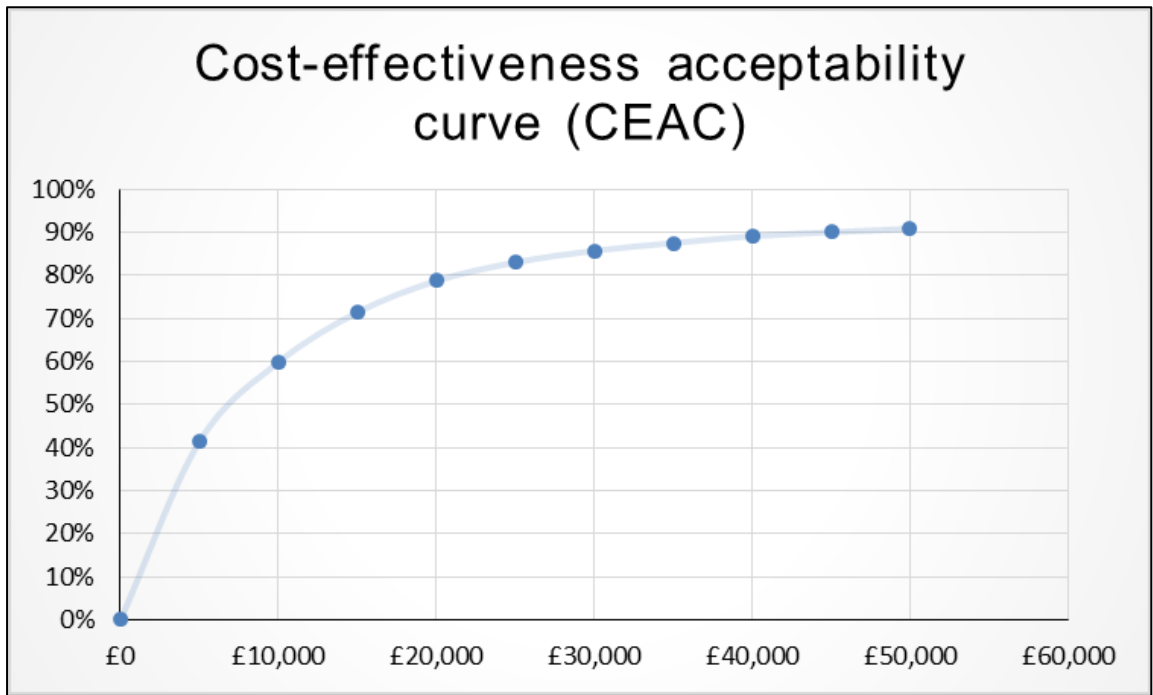
The impact of changing values of single parameters on the ICER was explored in one-way sensitivity analysis. This referred to parameters that the guideline committee considered uncertain and that were likely to have an important impact on the ICER.

In particular, the mean duration of ACP discussions was thought to be potentially much shorter than the one estimated for the base case. It was estimated that the average duration of ACP discussions was 2 hours instead of 4 hours. This was also supported by evidence from Detering et al. (2010), which found that the average duration of ACP was as short as 1 hour and the maximum duration was 2 hours. Graphs 6 and 7 show the impact on the results. The cost-effectiveness plane (Graph 6) showed that the majority of dots were under the red lines for both thresholds signalling that ACP had a probability to be cost-effective of above 50%; Graph 7 showed that the probability that ACP was cost-effective was just under 80% at a threshold of £20,000 per QALY and almost 90% for a threshold of £30,000 per QALY. The mean ICER was £8,322 per QALY.

Graph 6: Cost-effectiveness plane showing results of one-way sensitivity analysis, with mean duration of ACP discussions of 2 hours



1 Graph 7: Cost-effectiveness acceptability curve showing results of one-way sensitivity
2 analysis, with mean duration of ACP discussions of 2 hours



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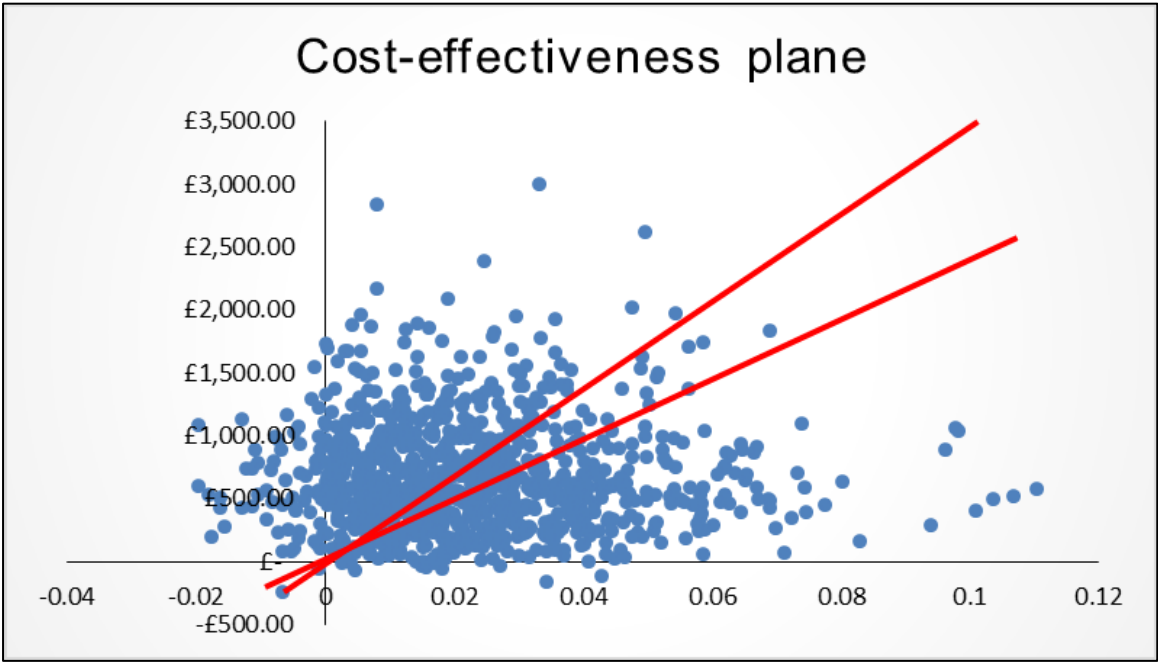
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6 Next, the impact of changing the duration over which carers (in the standard care group)
7 were assumed to experience health-related quality of life loss due to mental health problems
8 was explored. It is important to note that only people in the standard care group experienced
9 mental health problems. This was based on findings from Detering et al. (2010), which
10 showed that none of the carers in the ACP reported mental health problems. In one-way
11 sensitivity analysis the mean duration was changed from 0.42 years to 0.25 years. This
12 reflected the midpoint if the minimum time that people in the standard care group
13 experienced mental health problems was changed to 0 (maximum time was kept at 0.5
14 years). The mean ICER was £31,486 per QALY and the probability that ACP was cost-
15 effective as standard thresholds was only just above 30% at a threshold of £20,000 and 50%
16 at a threshold of £30,000 per QALY (Graphs 8 and 9).

17

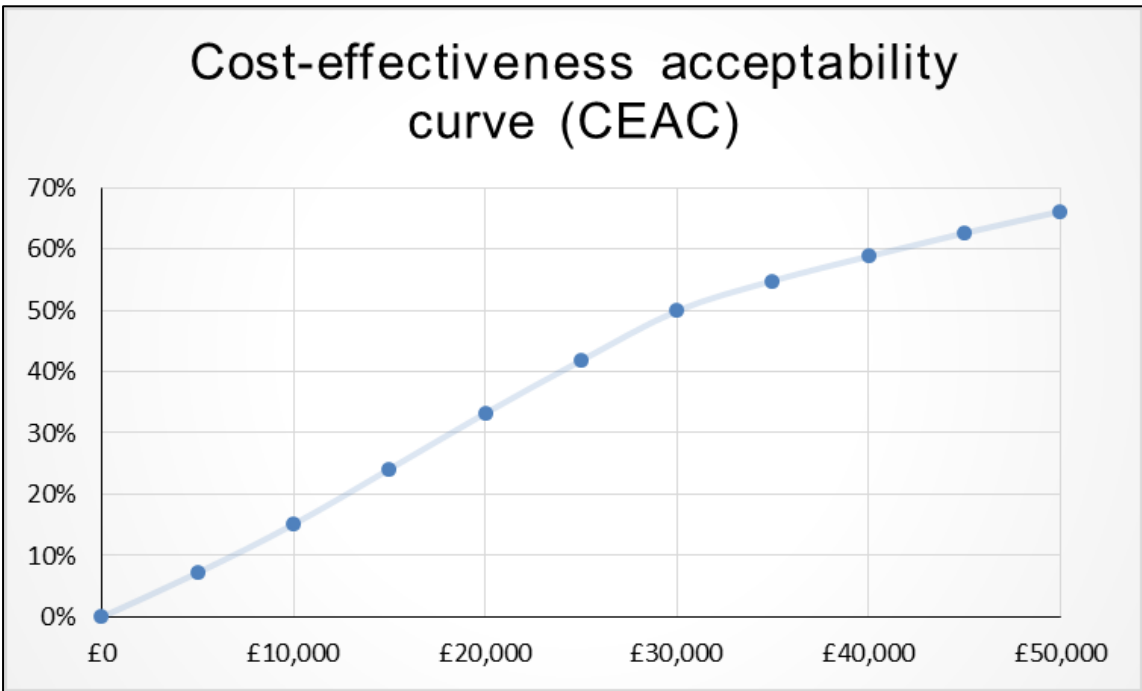
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1 Graph 8: Cost-effectiveness plane showing results of one-way sensitivity analysis, with
 2 mean duration of mental health problems experienced by carers (in standard care) of 0.25
 3 years



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6 Graph 9: Cost-effectiveness acceptability curve showing results of one-way sensitivity
 7 analysis, with mean duration of mental health problems experienced by carers (in standard
 8 care) of 0.25 years

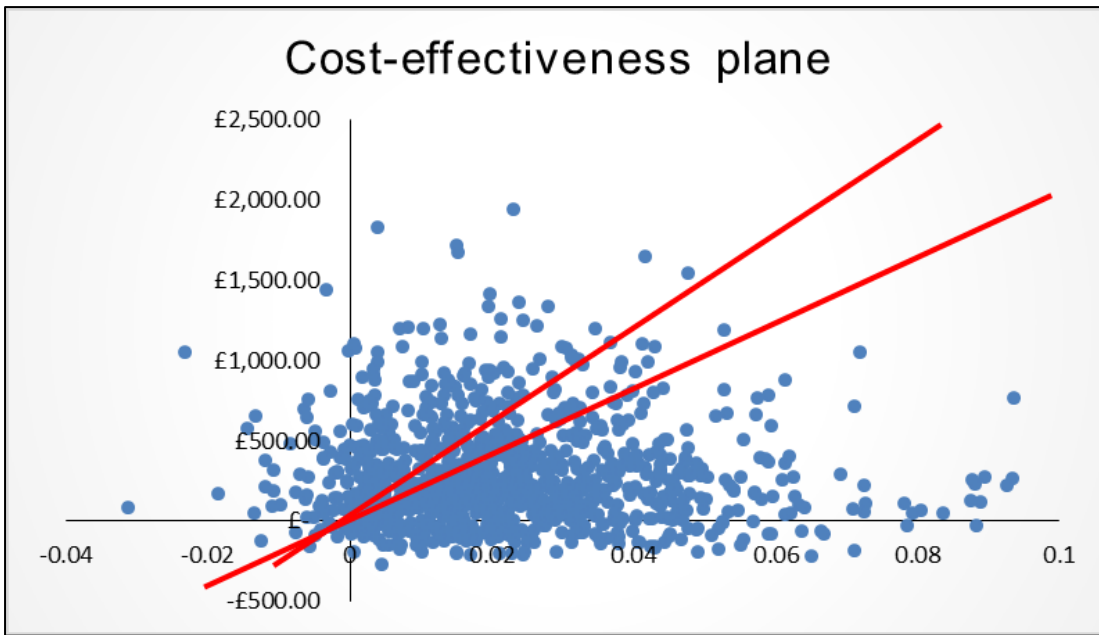


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11 A two-ways sensitivity analysis was then carried out to explore the impact of changing both
 12 parameters (mean duration of ACP discussions and mean duration over which carers

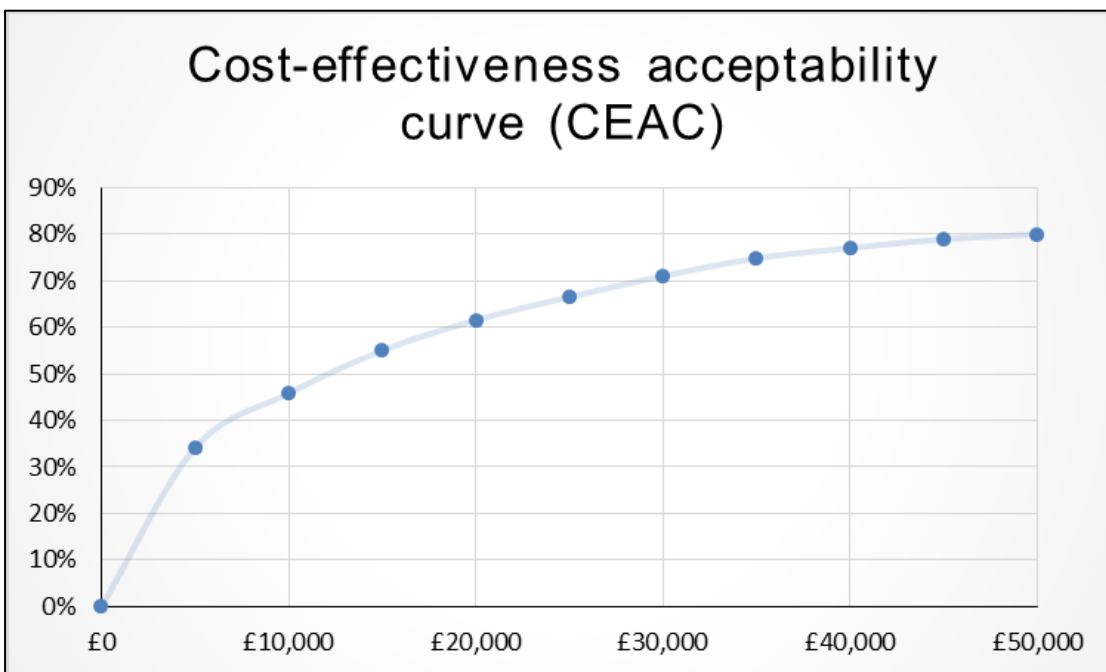
1 experienced mental health problems) at the same time on the ICER. The mean ICER was
 2 £13,591 if the mean duration of ACP was set to 2 hours and the mean duration that carers
 3 experienced mental health problems to 0.25 years. The probability that ACP was cost-
 4 effective was about 60% at a threshold of £20,000 per QALY and about 70% at a threshold
 5 of £30,000 per QALY (Graphs 10 and 11).

6 Graph 10: Cost-effectiveness acceptability plane showing results of two-ways sensitivity
 7 analysis, with mean duration of ACP of 2 hours and mean duration of mental health
 8 problems experienced by carers (in standard care) of 0.25 years



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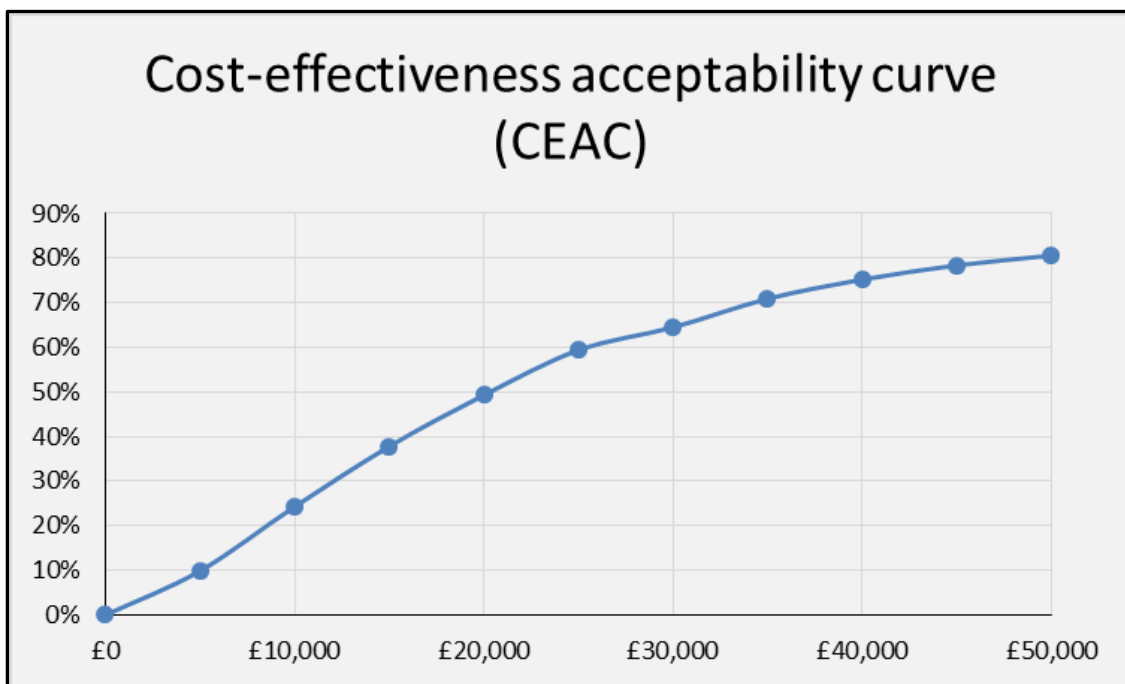
11 Graph 11: Cost-effectiveness acceptability curve showing results of two-ways sensitivity
 12 analysis, with mean duration of ACP discussions of 2 hours and mean duration of mental
 13 health problems experienced by carers (in standard care) of 0.25 years



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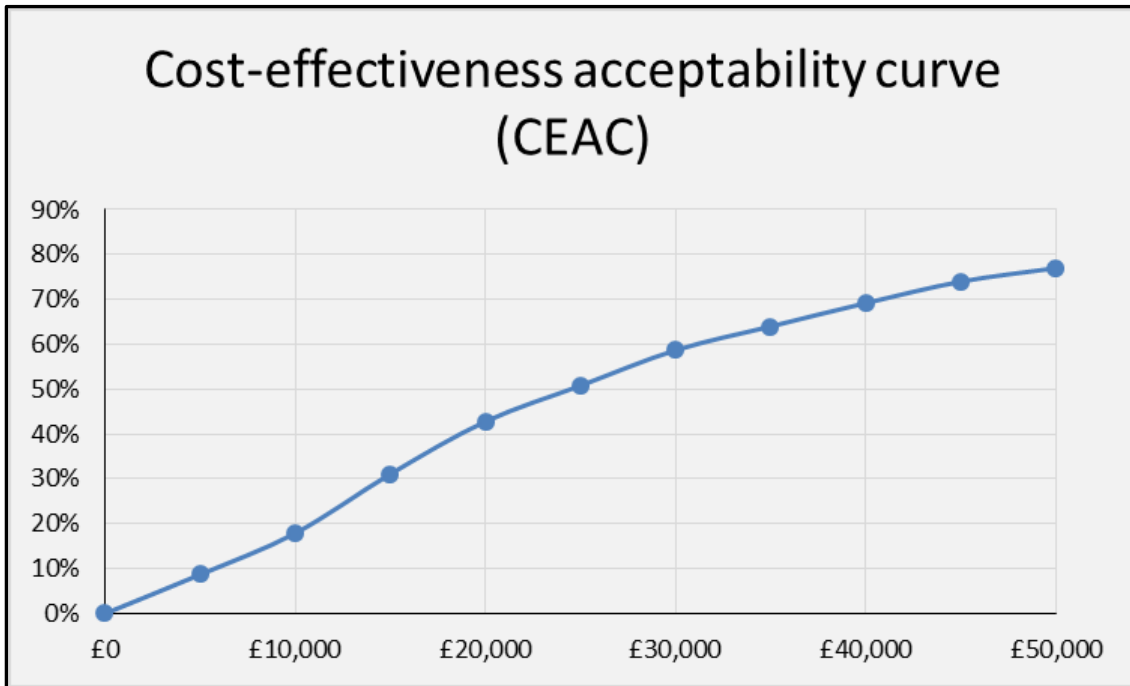
1 Finally, the impact of a higher prevalence of depression/anxiety in the intervention group
2 (which according to the Detering study was 0%) was tested. The resulting cost-effectiveness
3 acceptability curves (Graphs 12 to 14) show that for a threshold of £20,000 per QALY, ACP
4 was cost-effective if the prevalence was under 5% but not if the prevalence was higher than
5 5%. For a threshold of £30,000 per QALY, ACP was cost-effective if the prevalence was
6 under 15%. For a prevalence of above 15% ACP was no longer cost-effective compared
7 with standard care. Thus, findings were highly sensitivity to whether or not ACP was able to
8 reduce the prevalence of depression/anxiety in the ACP group. As before, if in two-ways
9 sensitivity a shorter mean duration of ACP discussions of 2 hours was assumed, then the
10 probability that ACP was cost-effective at prevalence of 15% in the ACP group was above
11 70%. It is also important to note that health-related quality of life benefits were likely to be
12 underestimated since only those to carers but not those to people dying were included.
13

14 Graph 12: Cost-effectiveness acceptability curve showing results of one-way sensitivity
15 analysis, with prevalence of depression/anxiety in ACP group of 5%



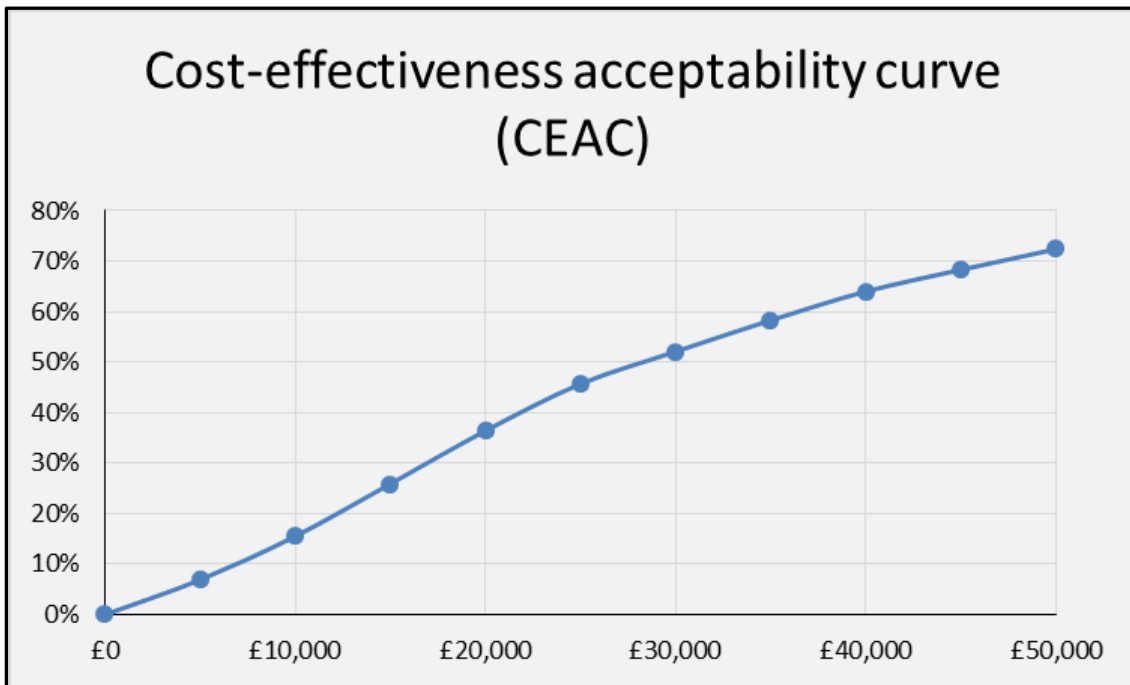
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1 Graph 13: Cost-effectiveness acceptability curve showing results of one-way sensitivity
2 analysis, with prevalence of depression/anxiety in ACP group of 10%



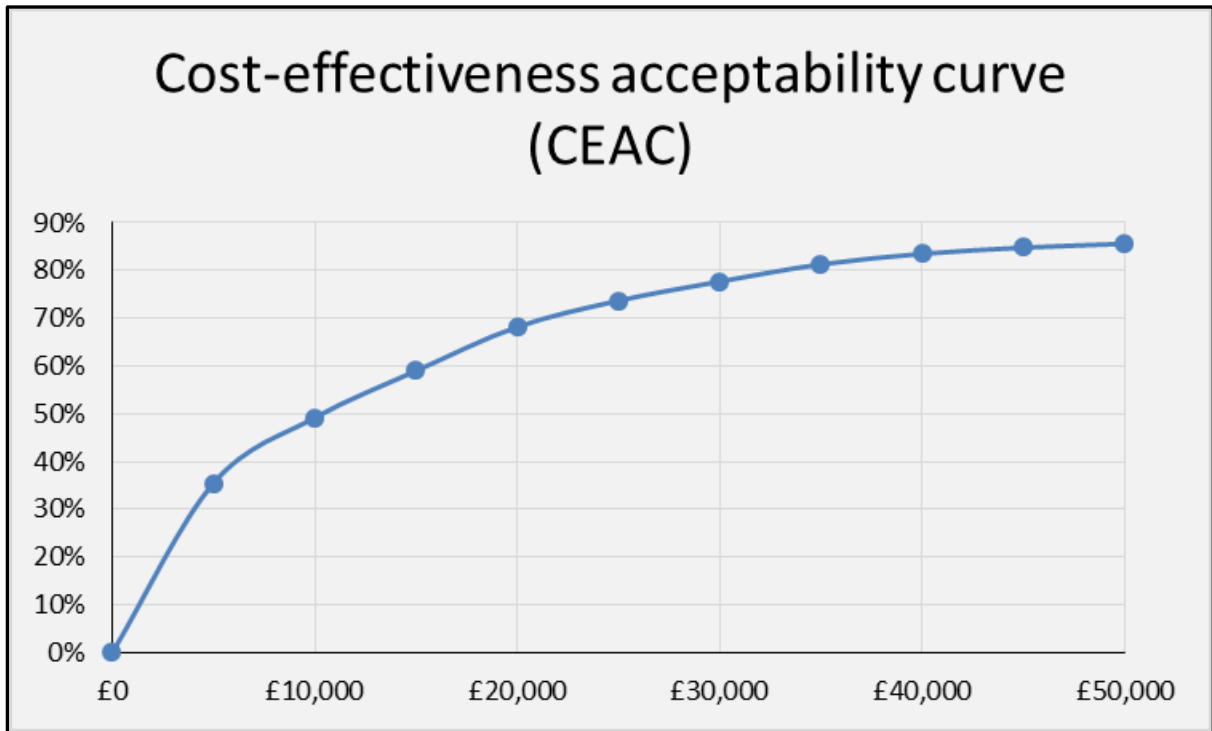
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5 Graph 14: Cost-effectiveness acceptability curve showing results of one-way sensitivity
6 analysis, with prevalence of depression/anxiety in ACP group of 15%



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- 1 Graph 15: Cost-effectiveness acceptability curve showing results of two-ways sensitivity
- 2 analysis, with depression/anxiety prevalence in ACP group of 15% and shorter duration of
- 3 ACP discussion of 2hrs



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9. Discussion

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14 The findings from the additional economic analysis showed that ACP could be provided cost-
 15 effectively with ICER for the base case of £16,925. The cost-effectiveness was strongly
 16 dependent on 3 parameters in particular: the duration of ACP discussions, the prevalence of
 17 depression/anxiety in the ACP group and the length of time that carers (in the standard care
 18 group) experienced those mental health problems. Sensitivity analysis showed that the
 19 influence of the mean duration of ACP was the factor that influenced the cost-effectiveness
 20 results most strongly: Even when a much lower QALY gain in the ACP group was assumed
 21 (which was considered either by increasing the prevalence of depression/anxiety in the ACP
 22 or by shortening the duration over which people in the standard care group experienced
 23 those mental health problems), ACP was still cost-effective if the mean duration of ACP
 24 discussions was 2 hours (instead of the 4 hours assumed for the base case). It is important

1 to note that health-related quality of life improvements were likely to be underestimated since
2 only those of carers but not of people dying were included. Overall, the probability that ACP
3 is cost-effective seems likely if ACP discussions do not last longer than 2 hours. Costs of
4 ACP were estimated using a conservative approach by including the whole process of ACP
5 including identification and assessments of mental capacity and by including the costs of a
6 wide range of practitioners who received training and attended ACP discussions.

7 The analysis had a number of limitations. The impact of ACP on service and outcomes was
8 based only on a limited amount of evidence primarily from 2 studies, 1 of which was a RCT
9 carried out in Australia and 1 was a cohort study carried out in England. While both studies
10 appeared to be of good quality they had their strengths and limitations. For example, the
11 study by Detering only measured mental health outcomes at one time point after the
12 intervention. Although the study had a randomised design the possibility that there were
13 differences in outcomes at baseline could not be excluded. Furthermore, mental health
14 outcomes were only measured for carers of people who died during the study period and
15 thus referred to a smaller study population of 56 individuals. An additional challenge was that
16 the study was from Australia and it was less clear how findings would translate into the
17 English context. A number of steps were taken to address this challenge: Additional English
18 data from nationally representative sources were used (for example, on number of cardiac
19 arrests and assisted ventilations) and applied to the outcomes measured in the Australian
20 study (such as number of wishes expressed and wishes being followed regarding
21 cardiopulmonary resuscitation and LPT). In addition, data to value the consequences (CPR,
22 LPT and place of death) were based on unit costs from national (English) sources. In
23 addition, data on place of death were used from the English study by Dixon et al. (2016).
24 The study by Dixon et al. (2016) had the advantage that it was an analysis of a large
25 representative population in England. However, it had the disadvantage that it was not an
26 evaluation of a specifically defined ACP approach. Instead, it measured the correlation
27 between recorded preference of death and actual place of death assuming that if the
28 preference of death was recorded, an ACP discussion had taken place.

29 An important challenge for this economic analysis of ACP was that the intervention (like
30 other complex interventions) is typically less well defined and potentially refers to a range of
31 heterogeneous interventions. In this analysis, an approach was taken to establish a model of
32 good practice ACP in an iterative knowledge exchange process with members of the
33 guideline committee. Although not identical to the ACP intervention evaluated by Detering et
34 al. (2010), it covered similar components and principles and the guideline committee
35 members referred to Detering's Respecting Patient Choices model in their discussions of
36 ACP. The Respecting Patient Choices model evaluated in Detering et al. (2010) was derived
37 from the Respecting Choices programme, which had been successfully implemented in a
38 number of countries in Europe, Australia, the US and Canada. Principles of the programme
39 reflected the focus of the ACP model agreed by the guideline committee members and
40 included a 'coordinated, systematic approach, patient centred approach' (Detering et al.
41 2010, p1). Thus the findings from the analysis produced for this Guideline referred to ACP as
42 a comprehensive, collaborative process that includes the involvement of a wide range of
43 professionals, carers and family members or friends. No conclusions can be drawn about
44 other types of ACP. For example, previously the focus of ACP has been on improving
45 completion on advance directives (Prendergast 2001).

46 The analysis reflected the perspective of the government, more specifically of the NHS and
47 Personal Social Services (PSS). The costs linked to wider societal impact were not included.
48 This means in particular that the impact on carers' hours of unpaid care was not considered.
49 The place of death, as an outcomes influenced by ACP, will also have an impact on the

1 burden of the carer, who will possibly take on additional caring responsibilities for people
2 dying at home. For example, Dixon et al. (2016) showed that having a carer strongly
3 influenced the likelihood of the person dying at home. Reasons for this are likely to be
4 complex but possibly include the availability of someone being able to provide unpaid care
5 (in addition to publicly funded care). Caring for someone at home at the end of life can have
6 a substantial impact on carers; for example, a study by McCrone (2009) showed that the
7 hours of unpaid care for a carer living with a person with dementia, multiple sclerosis and
8 Parkinson's disease were 75 per week whereas the hours of unpaid care provided for a
9 person living outside of their own home was 4 per week. The number of hours cared for will
10 strongly depend on a range of factors including the clinical condition and the provision of
11 care. In this model, the cost of unpaid care was not included; instead the cost of the
12 community support package was included and it was assumed that this covered the care
13 needed in the final days of life.

14 Furthermore, while the model referred to the time period of 1 year before end of life
15 (reflecting the length of time over which ACP discussions can take place), evidence only
16 supported the inclusion of costs for which there was evidence that ACP affected those. It is
17 thus not a comprehensive representation of all costs that occurred in the period of 1 year.
18 Instead the focus was on costs that were known to be influenced by ACP and most costs
19 referred to the time around death. Further research is needed to establish if ACP has a
20 longer-term impact on costs. In terms of outcomes, only the health-related quality of life of
21 carers could be included. It was summed that those impacts were short-term and ended
22 around the person's time of death or shortly after. Further research is needed to examine
23 whether there are long-term impacts of ACP on carers' health and wellbeing.

24 In terms of the implications of these findings for practitioners, commissioners and policy
25 makers, it is important to highlight that good practice ACP as set out by the guideline
26 committee is likely to require system changes. Costs of those system changes were not
27 included in this work. For example, systems need to be in place to allow the identification of
28 individuals who might benefit from ACP, collaborative working as well as the documentation
29 and sharing of information. Training and other educational as well as awareness raising
30 activities are likely to be required to ensure the cost-effective implementation of ACP.

31 Findings of the report also need to be interpreted in the context of law and government
32 policy. The UK government has emphasised the urgency of raising public awareness of
33 advance decisions to refuse decisions (House of Lords 2015, HM Government 2014). This is
34 in response to the very low uptake of advance decisions in England and Wales, which has
35 been reported to be the lowest among most other high-income countries. For example, most
36 Western European countries report uptakes between 10% and 20% in the general
37 population, whereas uptake in England has been estimated at 4% and in Wales at 2%
38 (Kitzinger and Kitzinger 2016). ACP as a personalised process, in which people are given an
39 opportunity to discuss their wishes, preferences and values based on detailed medical
40 information is likely to improve the uptake of advance decisions and thus support the rights
41 of individuals as set out in the Mental Capacity Act 2005.

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