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VALUING HEALTH AT THE END OF LIFE: A REVIEW OF STATED PREFERENCE STUDIES IN THE SOCIAL SCIENCES LITERATURE

Koonal K Shah

Office of Health Economics, UK

School of Health and Related Research, University of Sheffield, UK

Aki Tsuchiya

School of Health and Related Research, University of Sheffield, UK

Department of Economics, University of Sheffield, UK

Allan J Wailoo

School of Health and Related Research, University of Sheffield, UK

Corresponding author: Koonal K Shah (kshah@ohe.org)

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Abstract

A source of debate in the health care priority setting literature is whether to weight health gains to account for equity considerations, such as concern for those with very short life expectancy. This paper reviews the empirical evidence in the published social sciences literature relevant to the following research question: do members of the public wish to place greater weight on a unit of health gain for end-of-life patients than on that for other types of patients? An electronic search of the Social Sciences Citation Index for articles published until October 2017 was conducted, with follow-up of references to obtain additional data. Hierarchical criteria were applied to select empirical studies reporting stated preferences relating to hypothetical health care priority setting contexts.

Twenty-three studies met the inclusion criteria and were included in the review. Choice exercises were the most common method used to elicit preferences; other approaches included budget allocation, person trade-off and willingness-to-pay. Some studies found that observed preferences regarding end-of-life patients are influenced by information about the patients' ages. Overall, the evidence is mixed, with eight studies that report evidence consistent with a 'premium' for end-of-life treatments and 11 studies that do not. Methodological and design aspects that appear to influence the findings of end-of-life-related preference studies are identified and discussed. The findings of the UK studies have particular relevance for assessing the legitimacy of the National Institute for Health and Care Excellence's policy for appraising life-extending end-of-life treatments.

Key words

end of life; literature review; stated preferences; public preferences; societal preferences; priority setting; health economics; NICE

Introduction

A source of debate in the health care priority setting literature is whether and how to weight health gains to account for equity considerations. Assuming it is deemed appropriate to apply equity weights to health gains, and irrespective of the precise way in which the weighting system operates, the direction and magnitude of the weights are matters of value judgement (Brazier et al., 2017). The importance of public participation in health care decision-making has been emphasised in countries such as the UK (Department of Health, 1997), where members of the public are both potential users and (as taxpayers) the ultimate funders of the country's health service. Accordingly, most empirical studies examining the relative value of a quality-adjusted life year (QALY) have involved surveys using general public samples (Brazier et al., 2017).

Public preferences have been cited as a rationale behind the way in which life-extending end-of-life treatments are appraised by the National Institute for Health and Care Excellence (NICE). Since 2009, NICE has applied a supplementary policy which indicates that if certain criteria are met, it may be appropriate to recommend the use of such treatments even if their cost-effectiveness estimates exceed the range normally considered acceptable (NICE, 2009). However, there have been concerns that there is little evidence to support the premise that society places special value on life-extending end-of-life treatments (Rawlins et al., 2010). This has led to calls for evidence and further exploration of the issues (Green, 2011; Webb and Paterson, 2016).

The aim of this paper is to review the published social sciences literature that is relevant to the following research question: do members of the public wish to place greater weight on a unit of health gain for end-of-life patients than on that for other types of patients? Policies reflecting such preferences can be described as an 'end-of-life premium' (Cookson, 2013; McCabe et al., 2016). The review is in part motivated by the policy context in the UK, but the research question is pertinent in all countries seeking to understand whether there is societal support for prioritising the treatment of patients with short life expectancy. It adds to the existing literature on health care priority setting preferences, including a recent review investigating the evidence on preferences regarding the weighting of health gains for cancer patients (Morrell *et al.*, 2017).

The review focuses on studies concerned with the prioritisation of treatment based on patients' life expectancy (or proximity to death), thus distinguishing it from previous reviews of severity of illness more generally (Shah, 2009; Nord and Johansen, 2014), which typically have examined studies describing severity in terms of quality-of-life.

Methods

SSCI search

The primary source of data for the review was an electronic search of the Social Sciences Citation Index (SSCI) within the Web of Science Core Collection, first carried out in May 2014. The search was repeated in October 2017 in order to update the review. No time or language limits were imposed, though the database only covers articles published since 1956.

An iterative approach was used to identify search terms. The following sub-section therefore includes selected intermediate results, as necessary to explain the methods.

Search terms

Search terms were developed using an iterative process. The initial search terms were *end-of-life* and *preferences* (note that Web of Science automatically helps to find plurals and variant spellings). In order to improve the sensitivity of the search, two terms related to end-of-life – *severity* and *terminal* – were added. In a review of severity as a priority-setting criterion (Shah, 2009), some of the studies identified measured severity in terms of life expectancy. In its supplementary guidance on the appraisal of life-extending end-of-life treatments, NICE (2009) refers to the benefits of such treatments being achieved "in the later stages of terminal disease" (paragraph 2.2.1).

A form of 'word frequency analysis' (Glanville *et al.*, 2006) was then used to identify further search terms, in order to improve the specificity (and therefore the efficiency) of the search. Three articles were designated as 'key papers' (Abel Olsen, 2013; Linley and Hughes, 2013; Shah *et al.*, 2014) and their abstracts were examined. These were the only three fully-published articles that explicitly investigated public preferences regarding end-of-life treatments, as defined by the NICE guidance (and therefore of direct relevance to the policy issue that motivated this programme of research), that were known to the authors at the time of developing the search strategy. Some discussion/working papers that addressed the topic were also known to the authors, but these articles were not used for the purpose of identifying search terms because they had not yet been published in peer-reviewed journals and their abstracts were therefore subject to change.

All of the unique words that appeared in at least two of the three key paper abstracts were identified, and those considered to be potentially relevant to the research question were selected. The impact of adding these terms to the search was tested by examining whether their inclusion substantially reduced the number of records identified whilst increasing the specificity of the search. This was judged informally by assessing the number of 'probably relevant' records within the most recent 20 records. As a result of this process, the terms *health* and *respondents* (or its synonyms: *subjects*, *participants*, *sample*) were added. The term *life expectancy* was also added as a further alternative to *end-of-life*.

Box 1 shows the final strategy (note that TS refers to topic search, covering terms in the titles and abstracts of articles, as well as in the keywords that have been assigned to the articles by the authors and Web of Science).

<Box 1 here>

Selection of studies for inclusion

To be included, articles had to meet the following hierarchical criteria:

1. **Publication**: Article must be published in English and as a full text manuscript in a peer-reviewed journal.
2. **Empirical data**: Article must review, present or analyse empirical data.
3. **Priority-setting context**: Article must relate to a health care priority-setting or resource allocation context. Articles reporting preferences from an individual or 'own health' perspective (rather than a social decision-maker perspective) can be included as long as they clearly seek to inform health care priority-setting policies.
4. **Stated preference data**: Article must report preferences that were elicited in a hypothetical, stated context using a choice-based approach involving trade-offs.
5. **End-of-life**: Article must inform the topic of society placing greater weight on a unit of health gain for end-of-life patients (i.e. patients with short life expectancy) than on that for other types of patients.
6. **Original research**: Article must present original research and must not be solely a review of the literature.

Criterion 3 was applied to ensure that the review focused on studies that can inform the kinds of priority-setting policy issues faced by NICE and other similar agencies. The exclusion of articles reporting preferences only from an individual or 'own health' perspective was considered, as the legitimacy of using such studies to inform decisions about how to allocate shared resources has been questioned (Brouwer and Koopmanschap, 2000). However, it was deemed appropriate not to apply this exclusion rule on the basis that the own health perspective studies may provide information that is relevant to the research question.

Titles and abstracts were screened for eligibility against criteria 1 to 4, sequentially. The full texts of potentially eligible articles were then screened against criteria 1 to 6, sequentially. Full texts were also screened in cases where it was not clear from the title and abstract which of the criteria had and had not been met.

Whitty *et al.* (2014) and Gu *et al.* (2015) both note that there is currently no single standardised method for assessing the quality of stated preference studies covering the full range of preference elicitation techniques (though best practice guidelines do exist for specific methods – e.g. Bridges *et al.*, 2011). Hence, a formal assessment of study quality was not undertaken.

Identification of additional material

Additional material was identified by following up the reference lists of the articles whose full texts were screened. The same criteria were applied to these newly identified articles.

Data extraction

Data were extracted and compiled in an Excel database by author KKS. Following Whitty *et al.* (2014), it was deemed inappropriate to synthesise the preference data due to the variation in methods and contexts between studies, so a largely descriptive reporting approach was used.

Results

Literature search output

The final (October 2017) SSCI search yielded 899 unique results (Figure 1). By comparison, the May 2014 search yielded 598 unique results. Following the review of titles and abstracts (in which inclusion criteria 1 to 4 were applied sequentially), 817 of these were excluded, mostly for failing to meet criterion 3. Commonly excluded articles at this stage included: studies about advance directives (living wills); studies of people’s preferences for their own death and/or palliative care; studies focusing on the individual-level, bedside decision-making context; and health state valuation studies. Two of the articles excluded for failing to meet criterion 1 were published in German; the third was a conference abstract with no associated full text article.

Following a review of the full texts of the remaining 82 records (in which inclusion criteria 1 to 6 were applied sequentially), a further 67 were excluded. Commonly excluded articles at this stage reported public preferences regarding the prioritisation of health care resources based on severity (amongst other criteria) but did not define severity in terms of life expectancy, or did not report the results in such a way that preferences regarding life expectancy could be inferred.

<Figure 1 here>

The reference lists of the articles whose full texts were reviewed identified a further eight articles that were relevant to the research question but had not been picked up by the SSCI search, all of which met the criteria for inclusion. For example, two of these articles did not include the term *health* in their titles, abstracts or keywords. The additional articles met all six of the criteria for inclusion.

In cases where an article described a large study comprising multiple sub-studies with distinct methods and/or samples (e.g. Baker *et al.*, 2010), only the data for the sub-studies that were relevant to the research question were extracted.

Description of included studies

The included articles (Table 1) were published between 2000 and 2017, with the majority conducted and published after NICE issued its supplementary advice on end-of-life in January 2009. Ten of the studies (43.5%) used a solely UK-based sample, with the other studies originating elsewhere in Europe and in Australia, Canada, Japan, South Korea and the United States. Two studies included multi-country samples (Pennington *et* *al.*, 2015; Shiroiwa *et al.*, 2010). The distribution of key variables across the 23 articles is shown in Table 2. Full details are available in the supplementary appendix.

<Table 1 here>

<Table 2 here>

Methods used to elicit preferences

The majority of studies elicited preferences using some form of choice exercise whereby respondents were presented with multiple hypothetical patients (or patient groups) and were asked which they thought should be treated. In most cases the tasks involved pairwise choices, though Dolan and Shaw (2004) and Dolan and Tsuchiya (2005) both asked respondents to choose between six alternatives. Five of the choice exercise studies explicitly applied the DCE method as defined by Carson and Louviere (2011) – that is, an approach in which choices are made between discrete alternatives where at least one attribute is systematically varied in such a way that information related to preference parameters of an indirect utility function can be inferred.

A related approach, budget allocation, used in two studies (Linley and Hughes, 2013; Chim *et al.*, 2017), allows respondents to indicate the strength of their preference by specifying how funding should distributed among the candidate beneficiaries. The results of this method can be simplified by reporting, for example, whether respondents gave the majority of the budget to one group or another, or opted for an equal allocation between the groups.

Most of the studies used methods that are well-established in the field of health care preference elicitation (Ryan *et al.*, 2001). A more novel approach, which combined elements of the budget allocation and choice exercise techniques, was used in one study (Richardson *et al.*, 2012). Respondents were asked to allocate a set budget to one of the four patients (all of whom were the same age and faced immediate death without treatment), which would have the effect of extending their lives by 12, 8, 6 or 4 years, respectively. After allocating the first budget, they were then given a second budget (of the same size and with the same life-extending effects) to allocate in addition to the first. The procedure was repeated 30 times. Respondents' allocations gave an indication of whether they sought to maximise the number of years gained or to sacrifice overall gains by giving priority to the patient with the shortest life expectancy.

Another less established approach (in the field of health economics, at least) – Q methodology (Watts and Stenner, 2012) – was used in two studies (McHugh *et al.*, 2015; Wouters *et al.*, 2017). Q methodology combines qualitative and quantitative methods to study people's subjective opinions, values and beliefs (Baker *et al.*, 2006). Respondents in each study were presented with a set of statements describing views relating to the provision of end-of-life treatments. Following a structured process, they were asked to sort and position the statements on a response grid depending on whether they agreed with, disagreed with or were neutral towards them. They were then asked to articulate their views and to comment on statements that had been placed in the extremes of the grid. The researchers used factor analysis to identify underlying patterns in the resulting 'Q sorts'.

Four studies employed the willingness-to-pay method (Shiroiwa *et al.*, 2010; Shiroiwa *et al.*, 2013; Pinto-Prades *et al.*, 2014; Pennington *et al.*, 2015), in which respondents were asked whether and how much they would be willing to pay, from their own pocket, for a given improvement in health or life extension – or in the case of Pinto-Prades *et al.* (2014), for a specified chance of improvement. Respondents were generally expected to take an 'own health' perspective (i.e. to imagine that they were the beneficiaries of the treatment on offer) when completing the willingness-to-pay tasks. The other studies employed a 'social decision-maker' perspective whereby respondents were expected to make choices that they considered most appropriate and acceptable for society rather than those guided purely by self-interest. One study employed both an own health perspective, in willingness-to-pay tasks, and a social decision-maker perspective, in person trade-off tasks (Pinto-Prades *et al.*, 2014). Another study examined respondents' willingness-to-pay for life extensions not only for themselves but also for a family member (via an out-of-pocket payment) and for an unidentified member of society (via a tax increase) (Shiroiwa *et al.*, 2010).

One study compared two operationalisations of the social decision-maker perspective, asking half of the respondents to adopt the role of a decision-maker and assigning the other half to a ‘veil of ignorance’ condition (Dolan and Cookson, 2000). In one of the Q methodology studies, the vast majority of statements presented were framed in a manner consistent with a social decision-maker perspective, though a few referred to the respondent’s own health or situation – for example, “I wouldn’t want my life to be extending just for the sake of it – just keeping breathing is not life” (McHugh *et al.*, 2015).

Fourteen studies (60.9%) used modes of administration that required respondents to complete the tasks without an interviewer or moderator present to provide guidance. With one exception (Baker *et al.*, 2010), the DCE studies were all administered via internet surveys, most likely due to the ease of obtaining large samples with this mode. There has been a shift towards computer-based survey administration over time – the review included only four studies published since 2005 which did not use either an internet survey or computer-assisted personal interview approach.

Visual aids were used by 10 studies (43.5%), including all of the DCE studies. Thirteen studies (56.5%) permitted respondents to express indifference between or assign equal value to the alternatives presented. Fourteen studies (60.9%) reported that their design had been informed by piloting.

In each study, with the exception of the Q methodology studies, the size of the health gain was controlled for either in the design (e.g. by presenting equal-sized gains for all candidate recipients) or in the analysis.

Samples

Most of the studies used general public samples, though the extent to which the samples were representative of the relevant populations was mixed. McHugh *et al.* (2015) used a purposive sample comprising data-rich individuals (that is, individuals expected to have ‘rich, strong and different views’ on the topic) with different types of experiences or expertise in end-of-life in a professional or personal capacity. Wouters *et al.* (2017) included 10 respondents identifying as cancer patients or survivors in their sample.

Skedgel *et al.* (2015) and Kwon *et al.* (2017) both surveyed a small number of decision-makers with the aim of contrasting their responses with those of the general public. Stolk *et al.* (2005) used a convenience sample consisting of students, researchers and health policy makers – all of whom had some level of expertise in the topic of health care priority-setting.

The samples ranged from 23 individuals recruited from a single small city (Dolan and Shaw, 2004) to 17,657 individuals recruited from nine different countries (Pennington *et al.*, 2015). The seven largest-sample studies (n≥1,000) all recruited respondents from online panels.

End-of-life definitions

Nine articles (39.1%) explicitly mentioned end-of-life, or some synonym for end-of-life, in the stated study objectives. Of the remaining studies, some included end-of-life amongst several prioritisation criteria examined (e.g. Linley and Hughes, 2013), whilst others sought to answer an altogether different research question but happened to provide evidence relevant to end-of-life-related preferences indirectly (e.g. Richardson *et al.*, 2012). In the latter cases, preferences regarding end-of-life were inferred by extracting the results that could be used to draw conclusions about the values of a given gain for patients with different life expectancies (occasionally making calculations beyond those presented in the journal articles as necessary). End-of-life was most commonly presented in terms of patients' 'life expectancy' or 'remaining life years' if they did not receive the treatment, health care or transplant on offer. Other terms used included 'future years', 'urgency', 'fatal disease' and 'imminent death'.

A wide range of levels for the 'life expectancy without treatment' attribute (where applicable) was used. Some studies, none of which explicitly set out to examine preferences related to end-of-life, asked respondents to consider scenarios where patients would die immediately in absence of treatment, which meant in effect that their life expectancy without treatment was zero. In two studies (Stolk *et al.*, 2005; Baker *et* *al.*, 2010), information on the patients' life expectancy was not presented directly but could be calculated using the attributes that *were* included.

Most of the studies presented at least one alternative in which the patient or patient group would live for less than two years without treatment, which would make them potentially eligible for special consideration under NICE's criteria (NICE, 2009).

Comparators and other attributes examined

In the majority of studies, the key comparison – at least for the purposes of this review – was between an alternative describing a short, fixed amount of remaining life without treatment and one or more alternatives describing longer, fixed amounts of remaining life without treatment. Three studies, all of which applied the willingness-to-pay method, used different types of comparators (Shiroiwa *et al.*, 2013; Pinto-Prades *et al.*, 2014; Pennington *et al.*, 2015). These studies all included scenarios involving temporary quality-of-life losses, and sought respondents' willingness-to-pay to avoid those losses. One of the three studies also included a scenario involving a life extension at the end of the respondent's own stated life expectancy, and another involving spending time in a coma (Pennington *et al.*, 2015).

While several studies included attributes relating to quality-of-life gains, only three explicitly tested and reported whether respondents preferred quality-of-life improvements or life extensions for end-of-life patients (Pinto-Prades *et al.*, 2014; Shah *et al.*, 2014; Shah *et al.*, 2015a). Other studies collected the data required to make such comparisons possible but did not focus on quality-of-life in the published articles.

Ten studies (43.5%) purposely included information about age, thereby providing evidence on interactions and trade-offs between respondents' preferences regarding age and regarding end-of-life. One study (5%) attempted to control for time-related preferences by including questions designed to identify whether any observed preference for treating patients with shorter life expectancy is driven by a preference for the benefits of treatment to occur sooner rather than later (Shah *et al.*, 2014).

Findings of the studies

Evidence consistent with an end-of-life premium

Eight studies (34.8%) report evidence of support for placing greater weight on a unit of health gain for patients with relatively short life expectancy than on that for other types of patients. Their findings are summarised briefly below (presented in chronological order).

Stahl *et al.* (2008) report that respondents preferred treating the patient who was closer to death until the difference in life expectancy was less than 1.1 months (beyond which they showed no preference for the patient with shorter life expectancy). They also report that when one patient was set to gain a shorter life extension than another, the former needed to have a shorter life expectancy without treatment in order to be given priority overall (up to a threshold).

Shiroiwa *et al.* (2010) report that in all six countries examined, higher willingness-to-pay values were observed in scenarios where respondents had zero years of life expectancy than in scenarios where they had five years of life expectancy.

Lim *et al.* (2012) report that higher priorities were given to patients with less remaining life, noting that that respondents overall were willing to give up a 0.39 QALY gain in order to treat the patient whose life expectancy without treatment was one level (usually five years) lower.

Pinto-Prades *et al.* (2014) report that six- or 18-month life extensions for end-of-life patients were valued more highly than temporary quality-of-life improvements for non-end-of-life patients that were equivalent in terms of the number of QALYs gained. They note that this result was observed in both the willingness-to-pay and the person trade-off surveys, though the patterns of responses differed across the two methods.

Rowen *et al.* (2016a) report results that showed support for an end-of-life premium across different regression models, with evidence of a preference for treating patients with shorter life expectancy without treatment. However, the responses to their follow-up (attitudinal, non-choice-based) questions appear to contradict this finding.

Shah *et al.* (2014) report that the majority of respondents chose to give a six-month life extension to the patient with one year left to live without treatment rather than to the patient with 10 years left to live without treatment. However, they also noted that a non-trivial minority of respondents expressed the opposite preference.

Pennington *et al.* (2015) report that the mean and median willingness-to-pay values for one QALY worth of life extension achieved in the scenario of 'imminent, premature death from a life threatening disease' were considerably larger than those for an equal-sized gain achieved at the end of respondents' self-predicted life expectancy.

Kwon *et al.* (2017) report that 'disease severity' (defined in terms of the likelihood of dying within five years) was one of the three most preferred criteria for reimbursement decisions, alongside clinical benefits and cost-effectiveness.

Evidence not consistent with an end-of-life premium

Eleven studies (47.8%) report evidence that people do *not* wish to place greater weight on a unit of health gain for patients with relatively short life expectancy than on that for other types of patients.

Dolan and Shaw (2004) report that the majority of respondents chose to give priority to the patient with the longest life expectancy without a kidney transplant and who stood to gain the most from receiving the transplant. When it was later revealed that the end-of-life patient was the oldest of the six candidate recipients, none of the respondents chose to give the transplant to that patient.

Dolan and Tsuchiya (2005) report that respondents priority ranked end-of-life patients lower than corresponding non-end-of-life patients for all levels of age and past health. They also note that the coefficient for future years (life expectancy without treatment) as a main effects variable was not statistically significant.

Stolk *et al.* (2005) report priority rankings (based on respondents' choices in paired comparison tasks) of 10 conditions that correlated poorly and non-significantly with the theoretical ranking implied by a 'priority to shorter life expectancy' approach. Other theoretical rankings (severity, fair innings, proportional shortfall) were all significantly correlated with the observed ranking. Respondents were less concerned about life-threatening conditions for the elderly than prospective health theories that ignore the past (i.e. age) would have predicted.

Abel Olsen (2013) reports evidence of strong support for the fair innings argument, noting that respondents' choices were not affected by differences in patients' remaining lifetime without treatment.

Linley and Hughes (2013) report that, when faced with a choice between treating one patient group with a life expectancy of 18 months and another patient group with a life expectancy of 60 months, about two-thirds of respondents opted not to allocate more resources to the end-of-life group. The most popular choice was to allocate an equal amount of funding to both groups.

Shiroiwa *et al.* (2013) report that the proportions of respondents willing to pay an initial bid value for gains worth 0.2 or 0.4 QALYs were consistently lower in end-of-life scenarios than in non-end-of-life scenarios. Further, the average willingness-to-pay per QALY values observed in the end-of-life scenarios were generally lower than in the non-end-of-life scenarios.

Shah *et al.* (2015a) report a statistically significantly negative coefficient for the life expectancy without treatment variable, but noted that it was very small in magnitude compared to the health gain coefficients and had very little impact on the choices made by respondents. An end-of-life dummy variable defined purely in terms of life expectancy without treatment was found to have a small and non-significant coefficient.

Skedgel *et al.* (2015) report evidence of statistically significant and negative (positive) welfare effects associated with prioritising patients with the shortest (longest) level of initial life expectancy.

Rowen *et al.* (2016b) report an approximately equal split between choosing to treat a patient group with a life expectancy of five years and choosing to treat another patient group with a life expectancy of 10 years. Tests of association conducted by the authors indicate that this result did not depend on the mode of administration, wording of the question, or use of visual aids.

Chim *et al.* (2017) report that, when faced with a choice similar to that in Linley and Hughes (2013) above (between treating one patient group with a life expectancy of 18 months and another patient group with a life expectancy of 60 months), about three-quarters of respondents opted not to allocate more resources to the end-of-life group. Consistent with Linley and Hughes (2013), the most popular choice was to allocate an equal amount of funding to both groups.

Wouters *et al.* (2017) report that three 'viewpoints' (shared perspectives) emerged from their data, but in none of those viewpoints did they find direct support for making a special case for life-extending treatments for end-of-life patients.

Studies reporting mixed or inconclusive evidence

Four studies (20%) reported evidence that cannot easily be interpreted as being clearly consistent or inconsistent with an end-of-life premium. This was either because of heterogeneous preferences or because the observed results were not sufficiently robust.

Dolan and Cookson (2000) report that when asked to choose between giving a 10-year life extension to one patient group with 10 years of life expectancy without treatment and another with 30 years of life expectancy, 2% of respondents chose the latter; 50% chose the former; and 48% gave the same priority to both groups.

Baker *et al.* (2010) assessed preferences for different scenarios relative to a reference scenario of treating 40 year old patients expected to die at 60 years with a 0.7 quality-of-life loss without treatment. They report that in scenarios which were purely life-saving (i.e. involving immediate death without treatment), a preference was observed for treating patients aged 10 years relative to the reference scenario (controlling for the size of QALY gain). For other ages (1, 40 or 70 years), the reference scenario was preferred to the life-saving treatments. Similarly, life-saving treatments for 10 year old patients were preferred to treatments (offering the same QALY gains) for 10 year old patients who would not die immediately if left untreated, whilst the opposite was observed for patients of other ages.

Richardson *et al.* (2012) report that the majority of respondents did not behave in a QALY-maximising manner, with 69% allocating one of their first four budgets to the patient who stood to gain least (a four-year life extension) rather than giving that budget to the patient who stood to gain most (12-year life extension). The authors note that the average respondent allocated resources in such a way that 62.6% of possible gains in life years were achieved, with 37.4% of gains sacrificed to achieve sharing. In their regression models, life expectancy is a dominating variable – across all choices, the greater a given patient's life expectancy, the smaller the probability of that patient receiving resources (i.e. further life extensions).

McHugh *et al.* (2015) identified three 'factors' (shared perspectives) in their analysis. The first factor describes the view that society's interests are best served by seeking to maximise population health, and that "terminal illness should not be treated as a special case" (p.9). The second factor emphasises patient choice and the right to life-extending treatment for patients who want it, though this right may apply to non-end-of-life as well as end-of-life conditions. The third factor permits cases where special value is placed on extending the life of end-of-life patients, but this value is not unconditional and must be weighed up against opportunity costs. The findings demonstrate the 'plurality of views' within society and the authors highlight the problems associated with determining policy based on simple majority votes.

Table 3 compares the distribution of selected variables of interest among studies that report evidence consistent with an end-of-life premium with those among studies that do not.

<Table 3 here>

Other findings of relevance

Most of the studies did not examine or report explicitly whether quality-of-life improvements or life extensions for end-of-life patients were preferred, though in some cases it would have been possible to examine this given the nature of the data collected. Two studies reported that respondents favoured quality-of-life improvements (Pinto-Prades *et al.*, 2014; Shah *et al.*, 2014); and one study reported that respondents favoured life extensions (Shah *et al.*, 2015a) – controlling for the size of health gain in all cases.

The majority of studies included patient age in the study design. In some cases age was one of several prioritisation criteria being examined; in other cases, the researchers were seeking to examine whether respondents' end-of-life-related preferences were influenced by the ages of the patients. The findings of two studies suggest that respondents become less concerned about the number of remaining life years when the patients in question are relatively old (Dolan and Shaw, 2004; Stahl *et al.*, 2008). One study did not find that concern about age is a motivating factor for giving priority to the treatment of end-of-life patients (Shah *et al.*, 2014), though the range of ages presented was narrow (nine years). Several studies reported evidence that respondents gave priority to younger patients, often without making an explicit link between age-related preferences and end-of-life-related preferences (Dolan and Cookson, 2000; Dolan and Tsuchiya, 2005; Stolk *et al.*, 2005; Baker *et al.*, 2010; Abel Olsen, 2013; Skedgel *et al.* 2015).

Time-related preferences were mentioned in only a few of the studies. One study reported evidence that patients who have only just learned their prognosis are given priority over those who have known about their prognosis for some time, controlling for life expectancy (Shah *et al.*, 2014). Another study interpreted differences between willingness-to-pay values in end-of-life and non-end-of-life scenarios in terms of time preference, and used the data to estimate discount rates (Shiroiwa *et al.*, 2010). Three studies acknowledged that their findings may have been influenced by respondents' time preference or that applying a positive discount rate in the analysis would have led to slightly (albeit not qualitatively) different results (Richardson *et al.*, 2012; Pennington *et al.*, 2015; Shah *et al.*, 2015a).

Two studies reported evidence that older respondents were more likely than average to make choices based on patients' life expectancy without treatment (Dolan and Tsuchiya, 2005; Stahl *et al.*, 2008). One of the willingness-to-pay studies reported that older age was associated with lower valuation for life extensions in the own terminal illness scenario (Pennington *et al.*, 2015). Other background characteristics found to be associated with respondents' priority-setting preferences were: education (Dolan and Tsuchiya, 2005; Shiroiwa *et al.*, 2010); employment status (Dolan and Tsuchiya, 2005); health status (Pennington *et al.*, 2015); health history of family members (Stahl *et al.*, 2008); and household income (Shiroiwa *et al.*, 2010). However, the majority of studies either did not observe any associations between background characteristics and preferences or did not report any such analysis. McHugh *et al.* (2015) found that none of the academic researchers in their sample helped to define the shared account most closely related to support for an end-of-life premium, though the authors warn against making generalisations based on qualitative samples.

Discussion

Twenty-three empirical studies that inform the research question of whether members of the public wish to place greater weight on a unit of health gain for end-of-life patients than on that for other types of patients were identified and reviewed. The number of studies addressing this topic has been growing – several were initiated following (and refer explicitly to) the issuing of NICE's end-of-life policy in January 2009. Many of the studies originated in the UK, which is unsurprising given the policy interest in NICE (an agency which make recommendations on the use of health technologies in England). The majority of the studies reviewed used a preference elicitation technique that can be described as a 'choice exercise', with an increasing number specifically applying the DCE method. This reflects the growing popularity of the method in applied health economics research (de Bekker-Grob *et al.*, 2012; Clark *et al.*, 2014), particularly in the field of health care priority-setting (Whitty *et al.*, 2014). DCEs are considered to enjoy a strong theoretical basis (Lancsar and Donaldson, 2005) and there is evidence that the method is feasible, flexible and capable of presenting choices that are relevant to respondents (Ryan and Gerard, 2003).

The primary finding of the review is that the existing evidence is mixed, with eight studies that report evidence consistent with a premium for end-of-life treatments and 11 studies that do not. Reviews of severity-related preferences more generally have been able to reach more decisive conclusions – Shah (2009) and Nord and Johansen (2014) both report an overall preference for giving higher priority to those who are severely ill – but as mentioned above the studies reviewed typically focused on severity in terms of quality-of-life, not length of life. Comparing the findings of the reviews of severity with those of the present review suggests that people are more likely to be concerned about treating patients with poor quality-of-life than with treating patients with short life expectancy. However, this supposition is not supported by individual studies that examined both simultaneously – Stahl *et al.* (2008), Shah *et al.* (2015a) and Rowen *et al.* (2016a) all report stronger support for giving priority to treating patients with relatively short life expectancy than to treating those with relatively poor quality-of-life, controlling for the size of health gain.

The evidence on whether quality-of-life improvements or life extensions for end-of-life patients is also mixed, with two studies reporting evidence of an overall preference for quality-of-life improvements, and one study reporting the opposite. It is noteworthy that the current NICE policy involves giving greater weight to life-extending but not to quality-of-life-improving treatments for those at the end-of-life. There is little evidence to suggest that such a policy is consistent with public preferences.

The overall findings of studies were summarised by assigning each to one of three categories: (1) consistent with an end-of-life premium; (2) not consistent with an end-of-life premium; and (3) mixed or inconclusive evidence. In absence of a clear definition of what counted as ‘support’, this exercise involved a degree of subjective judgement. It is rarely the case in stated preference studies that a unanimous preference is observed. There is usually a split in opinion, and a judgement then needs to be made about whether the minority view is held by a sufficiently large number of respondents (or held sufficiently strongly) so as to conclude that the evidence is inconclusive overall. As far as possible, the study authors’ own conclusions were used as a guide. This was not always possible, since some studies did not set out to examine end-of-life-related preferences directly and further subjective interpretation of the reported results was required. In cases where there was uncertainty about the conclusions of a given study, the corresponding author was contacted to check that they agreed with the proposed summary and categorisation of their findings.

The heterogeneity of preferences held by the general population is highlighted by McHugh *et al.* (2015) and Wouters *et al.* (2017), who each identified three distinct shared perspectives in their respective datasets. Other studies similarly identified multiple subgroups within their samples whose response patterns imply very different views about the value of end-of-life treatments (e.g. Pinto-Prades *et al.*, 2014; Shah *et al.*, 2015a). Given these findings, it is perhaps not surprising that this review has been unable to establish whether or not the overall evidence available in the literature is consistent with an end-of-life premium.

Majoritarian decision rules are common in politics and policy making, with most elections and referendums in modern western democracies being decided by majority rule. However, such approaches are criticised for failing to achieve outcomes that represent the views of all sections of society in a representative manner (Mill, 1861). A hypothetical example of a study that would be problematic to categorise based on majority rule is one in which a slight (but statistically significant) majority of respondents express *weak* support for an end-of-life premium and a sizeable minority *strongly* disfavour an end-of-life premium. Many of the studies in this review did not examine strength of preference at the individual respondent level and were not designed in such a way that nuances and caveats regarding respondents' stated preferences could be captured. The normative basis for specifying a measure of average or overall preference in social choices is unclear – in the context of aggregating preferences regarding health states, Devlin *et al.* (2017) conclude that there are no strong grounds for favouring any one approach.

Table 3 shows how studies that report evidence consistent with an end-of-life premium compare to those that do not. The number of studies included in the review is insufficient to permit meaningful testing of statistical associations, so any trends observed should be interpreted with caution. Nevertheless, there is weak evidence that studies were more likely to report evidence consistent with an end-of-life premium if they: used the willingness-to-pay method; allowed indifference to be expressed; or used visual aids. Each of these variables is discussed in turn below. It is acknowledged that the following sub-sections – particularly those relating to indifference options and visual aids – involve a degree of subjective judgement and speculation on the part of the authors.

Choice of method and perspective

Most of the studies in this review asked respondents to adopt a social decision-maker perspective – that is, they were asked to consider questions typically of concern to a health care decision-maker (such as whether one patient group or another should receive higher priority in the face of scarce shared resources) and to answer those questions based on what they consider to be appropriate and acceptable for society. The respondent (acting as decision-maker for the purpose of the study) would not necessarily expect to benefit personally from their choices. The four studies that used the willingness-to-pay approach, on the other hand, generally asked respondents to adopt an individual or own health perspective – that is, they were asked how much they would pay (from their own pocket) for a given improvement in their own health. This method is consistent with the welfarist view that confines the evaluative space to individual utility only – the 'goodness' of a policy can be judged solely on the basis of the utility gains and losses achieved by individuals affected by that policy (Brouwer *et al.*, 2008).

Three of the four willingness-to-pay studies report evidence consistent with an end-of-life premium, based on higher average willingness-to-pay values for a life extension in an end-of-life scenario than for a similar gain (e.g. worth the same number of QALYs) in a non-end-of-life situation. However, and as acknowledged by Pennington *et al.* (2015), willingness-to-pay valuations made by individuals facing the prospect of imminent death can be expected to be high because the opportunity costs in those circumstances are low or non-existent. Other than the ability to leave a legacy, money is arguably of no use to individuals when they are dead. This is often referred to as the 'dead-anyway' effect whereby an increase in an individual's mortality risk reduces their expected marginal utility of wealth (thereby increasing their willingness-to-pay) since the marginal utility of wealth when alive is greater than the marginal utility of wealth when dead (Pratt and Zeckhauser, 1996). It is therefore understandable and perhaps consistent with utility-maximising behaviour for individuals nearing their end-of-life to be willing to spend most or all of the money they have on extending their life, even if the utility gains from the life extension are small. If such willingness-to-pay values are then used to inform decisions about how to spend a common pool of funding that has been raised from members of the public (many of whom will not be at their end-of-life), then the opportunity cost of expenditure on end-of-life treatments will be higher as it would result in foregoing spending on other treatments. It may therefore be considered inappropriate to use willingness-to-pay values elicited from an individual perspective to inform society-level decision-making. It should be noted, however, that Shiroiwa *et al.* (2010) observed higher values for gains accruing to respondents' family members and to unidentified members of society than those accruing to the respondents themselves in five of the six countries studied. The authors suggest that this result may reflect altruistic preferences.

When developing the inclusion criteria for this review, it was deemed appropriate to include own health perspective studies that clearly sought to inform health care priority-setting policies. Some own health perspective studies that appeared to report results of potential relevance to the overall research question were nevertheless excluded on the basis that they did *not* clearly seek to inform health care priority-setting policies (e.g. Kvamme *et al.*, 2010). An alternative approach would have been to restrict the review to studies adopting a social decision-maker perspective. One of the studies that used the willingness-to-pay method would continue to be included in the review on the basis that it also reported preferences obtained using person trade-off tasks undertaken from a social decision-maker perspective (Pinto-Prades *et al.*, 2014). The study by Shiroiwa *et al.* (2010) would be excluded on the basis that it employed a social decision-maker perspective in only one task, involving a scenario describing imminent death, so comparisons between end-of-life and non-end-of-life social decision-maker valuations would not be possible. Applying such a restriction would result in a slightly different balance of findings across the studies: of the studies that would remain, five report evidence consistent with an end-of-life premium and eight do not.

Inclusion of indifference options

Studies that offered respondents the opportunity to express indifference between the alternatives on offer were more likely to report evidence consistent with an end-of-life premium than those that did not. The nature of the indifference options available differed across studies. In the choice exercise studies, options such as 'Can't decide' (Stahl *et al.*, 2008) and 'I have no preference' (Shah *et al.*, 2014) were presented. In the willingness-to-pay studies, respondents could express indifference by stating the same value for two or more different gains. In the budget allocation study, respondents could choose to split resources evenly between the two recipient groups. In the Q methodology studies, respondents were required to position some of the statements in such a way that implied neither agreement nor disagreement.

The way in which indifference options are framed can affect respondents' willingness to choose those options – for example, Shah and Devlin (2012) reported that respondents showed an attraction to a 50:50 split when asked to allocate a budget between two patient groups but an aversion to an 'I have no preference' option in a choice exercise involving the same two groups. This finding is supported by those of the present review – the two budget allocation studies both found that a 50:50 split was the most popular option. It may be that respondents consider a 50:50 split (but not an 'I have no preference' response) to be a legitimate choice when they find it difficult to choose between two options. Alternatively, they may be concerned about the implications of expressing indifference in a choice exercise – for example, they might be under the impression that failing to choose means that neither patient would receive the treatment on offer.

When respondents are indifferent between the available options but no indifference option is available, they are forced to make a choice in order to proceed. In principle, these respondents should make their choices at random, which will tend to result in a roughly even split between the available options in the choice data. In practice, respondents may pursue an alternative choice strategy. For example, when faced with a choice between treating an end-of-life patient and a non-end-of-life patient, a respondent may anticipate other respondents choosing to treat the end-of-life patient but may themselves consider both patients to be equally deserving of treatment. If this respondent wishes that both patients should be given an equal opportunity to be treated, they may then express a preference for treating the non-end-of-life patient (to counteract the choices they anticipate the other respondents making). This increases the likelihood of the study failing to find an overall preference for treating the end of patient. Evidence of such response behaviour has been discussed by Shah *et al.* (2015b).

It is common for DCEs and studies using internet surveys – both of which are becoming increasingly popular in this field – not to include opt-out or indifference options. For DCEs, best practice guidelines advise that indifference options are often inappropriate as they can have implications for the experimental design and lead to the censoring of data (Bridges *et al.*, 2011). For internet surveys, which are sometimes viewed with suspicion due to concerns about respondents' attentiveness, indifference options are often avoided on the grounds that they will be used a default choice, thus providing respondents with a way to avoid taking time to make difficult decisions. If studies are less likely to detect support for an end-of-life premium if they do not include an indifference option, and if the trend for studies not to include an indifference option continues, then it can be expected that fewer studies will report evidence consistent with an end-of-life premium going forward.

Use of visual aids

The use of visual aids appears to be increasing. Most of the studies published since 2014 included diagrams designed to help respondents make sense of the (often complex) choice tasks. These often took the form of figures depicting quality-of-life on one axis and length of life or time on the other. Visual aids were used in all five DCE studies reviewed, and in the majority of studies administered using a computer-based approach.

Studies that used visual aids were more likely to report evidence consistent with an end-of-life premium than those that did not. One possible explanation is that very short amounts of time (in most studies respondents were presented with scenarios in which at least one patient had less than 12 months left to live) appear starker and more dramatic when presented graphically than when described verbally.

It has been argued that graphs may not be the best way to present scenario information to survey respondents due to concerns that they unintentionally lead to different respondents interpreting the information in different ways (van de Wetering *et al.*, 2015). For example, when faced with diagrams in which better quality-of-life and longer life expectancies are represented by larger areas, some respondents may (subconsciously or otherwise) be attracted to the larger areas and therefore to the alternatives depicted by diagrams showing longer life expectancies.

Such framing effects are clearly a matter of concern, particularly in studies where no interviewer is present, since the opportunities for instructing and debriefing respondents are very limited. This makes it difficult to know for certain the extent to which the choice data truly reflect the respondents' beliefs and preferences, or whether the respondents interpreted and answered the questions as the researcher had intended them to. However, this concern is not restricted to the use of visual aids. One possibility is that respondents being presented with two or more hypothetical patients may mistakenly interpret the task as asking them which patient they would prefer to be in the position of rather than which patient they consider to be more deserving of treatment. It is not clear that such a misinterpretation would be more likely to occur in a survey using a combination of text and graphical descriptions than in one using only text descriptions. Indeed, if the issue is that respondents being presented with complex choice tasks do not always understand what is being asked of them, it seems intuitive to give them more, rather than less, assistance.

Further, if the use of visual aids encourages respondents either to choose the patient they would prefer to be in the position of, or to choose the alternative associated with larger areas, then this would in most cases result in them being more likely to choose to treat patients with longer rather than shorter life expectancies. This is inconsistent with the finding of this review that studies using visual aids were more likely to report evidence consistent with an end-of-life premium than those that did not. One study that used two different question frames to understand respondents' preferences regarding end-of-life found that many respondents expressed support for prioritising life-extending end-of-life treatments in the DCE tasks (which used visual aids) (Rowen *et al.*, 2016a). However, the same respondents then gave responses to more direct attitudinal questions (which did not use visual aids) that suggest that they did not believe that the NHS should give priority to such treatments. Furthermore, the one study that actively set out to examine the impact of visual aids found that the propensity to choose to treat the patient group with shorter life expectancy was unaffected by whether diagrams were used to illustrate the information (Rowen *et al.*, 2016b).

The findings of this review may suggest that the likelihood of a study providing evidence consistent with an end-of-life premium is linked to the choice of perspective and to whether indifference options and visual aids were used. However, it should also be noted that conflicting results were reported by two studies that did not differ in these respects. Shah *et al.* (2015a) and Rowen *et al.* (2016a) both used the DCE method with forced-choice tasks supported by visual aids (indeed, Shah *et al.* acknowledge that they based their design on that of the Rowen *et al.* study, using very similar graphs and text descriptions to present information to respondents). Both studies also used similar samples – members of the UK public recruited from online panels and broadly representative of the general population in terms of age and gender.

Limitations

Some limitations of the review should be mentioned. Only one database – the SSCI – was searched. It is acknowledged that similar reviews sometimes involve searches of multiple databases in order to increase the likelihood of identifying relevant studies from a broad range of journals. However, SSCI is an interdisciplinary database covering around 3,000 journals from across the social sciences, including most major health economics and health policy journals known to the authors. Indeed, seven of the eight additional studies identified through follow-up of references were published in journals that are indexed in SSCI.

The review included only articles that have been published in English. Only two records were excluded due to publication in a language other than English, but this could be linked to the choices made regarding data sources and the search strategy. On a related note, the review was to a large extent motivated by the policy context in the UK. The authors of this review identify as health economics researchers based in the UK (the same is true of many of the authors of studies included in the review). Hence, the search terms considered are likely to reflect the language used by this particular subset of the academic community and may not be well suited for identifying, say, articles authored by ethicists or by researchers based in low-income countries.

Whereas reviews of clinical trials are subject to rigorous guidance on search methods, data extraction and evidence synthesis (Centre for Reviews and Dissemination, 2009; Liberati *et al.*, 2009), such guidance is unavailable for reviews of stated preference studies. Although it cannot be claimed that the review is fully exhaustive, efforts have been made to be explicit about the methods used and balanced in the presentation of findings.

As mentioned above, a formal assessment of study quality was not undertaken due to the lack of a known, standardised method for doing so. Instead, publication in a peer-reviewed journal was relied on as a proxy for quality. None of the studies included in the review was judged to be of such poor quality that their findings ought to be disregarded. However, it is acknowledged that there may be studies that are relevant to the research question that have not been published in a peer-reviewed journal, such as those in the grey literature (for example, reports of NICE's Citizens' Council – see NICE, 2017) and working papers or theses that had not been submitted to or accepted by a journal.

The follow-up of reference lists of the articles whose full texts were reviewed was useful – eight of the 23 included articles (34.8%) were identified in this way. A further step would have been to search for articles that have cited those already identified, as in ‘snowballing’ or ‘citation pearl growing’ (Paisley, 2014).

Gaps in the literature

Given the possibility that the findings of stated preference studies are influenced by the choice of elicitation method or by characteristics of the study design, it would be informative for studies to use multiple methods or designs in order to test the robustness of their results. Most of the studies included in this review used a single method and design throughout. Exceptions to this include Pinto-Prades *et al.* (2014), who noted discrepancies between willingness-to-pay and person trade-off responses at the within-respondent level (though the same broad conclusion was reached using both methods); and Rowen *et al.* (2016b), who compared the results achieved using different modes of administration and question framings. A recent study by Gyrd-Hansen (2017) – published after the updated search for this review was undertaken – is informative in this respect as it elicits end-of-life-related preferences from both an individual and a social decision maker perspective (it is also novel in that it compares end-of-life treatments to preventive interventions).

A related issue is that few studies sought to understand whether respondents would agree with the researchers’ interpretations of their responses to the stated preference tasks. Rowen *et al.* (2016a) inferred from their DCE data that there was robust and consistent support for an end-of-life premium. Yet when asked about the prioritisation of end-of-life patients more directly later in the survey, the majority of respondents expressed views that implied the opposite conclusion. It would be informative for researchers to test the stability of respondents’ preferences – for example, by presenting the policy implications of their earlier choices and checking whether they agree with these (Whitty *et al.*, 2014; Shah *et al.*, 2015b). Studies applying techniques that are designed to allow unexpected views to emerge, such as Q methodology (as used by McHugh *et al.* (2015) and Wouters *et al.* (2017)), also offer promise for researchers seeking to make sense of apparently inconsistent or counterintuitive preferences.

Policy implications

Overall, the evidence on public preferences regarding the special weighting of end-of-life treatments is mixed. It should also be noted, however, that the studies conducted in the UK have not, on the whole, reported evidence consistent with an end-of-life premium. This has relevance for assessing the legitimacy of NICE's end-of-life policy, which was said to have been motivated at least in part by the views held by the population that the NHS serves (Rawlins *et al*., 2010). Based on this finding, it might be deemed appropriate for NICE to consider abandoning its end-of-life policy and any other mechanisms that relax the cost-effectiveness requirements for end-of-life treatments, on the grounds that the population health losses that arise due to the policy (Collins and Latimer, 2013) are not justified by the evidence on societal preferences. This would result in fewer approvals of end-of-life treatments, and therefore in reduced access to treatments for patients with terminal illness. In principle, of course, other, less identifiable groups of patients would benefit as the freed funding could be spent on health care that is more cost-effective and/or that the public values more.

It may be that there are compelling arguments for retaining some form of end-of-life weighting irrespective of public preferences. For example, if the standard QALY approach – used not only by NICE but also by similar agencies in many other countries – systematically underestimates the (health or non-health) benefits of end-of-life treatments (whether or not this is actually the case would itself need investigating), it may be appropriate to correct for this. An end-of-life premium may also help to encourage innovation, or to meet broader health system and political objectives. Finally, it is worth noting that once a prominent policy has been introduced, withdrawing it may be inherently and procedurally difficult – a point that should be heeded by countries contemplating the introduction of explicit weighting or prioritisation based on equity or other considerations.

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Table 1. Summary of included studies (n=20)

Authors (date)	Country	Sample size (type)	Method [a]	Mode of administration	Summary of primary study objective(s)
Abel Olsen (2013)	NOR	503 (public)	Choice	Internet survey	To test for support for end-of-life prioritisation and the fair innings approach
Baker *et al.* (2010)	UK	587 (public)	DCE	Computer-assisted personal interview	To test for support for multiple prioritisation criteria
Chim *et al.* (2017)	AUS	3,080 (public)	Budget allocation	Internet survey	To test for support for multiple prioritisation criteria
Dolan and Cookson (2000)	UK	60 (public)	Choice	Focus group (individual responses)	Qualitative examination of support for multiple prioritisation criteria
Dolan and Shaw (2004)	UK	23 (public)	Choice	Focus group (individual responses)	To test for support for multiple prioritisation criteria
Dolan and Tsuchiya (2005)	UK	100 (public)	Choice; ranking	Individual self-completion survey (completed in group setting)	To compare support for prioritisation according to age vs. prioritisation according to severity/life expectancy
Kwon *et al.* (2017)	ROK	300 (public); 30 (decision-makers)	Analytic hierarchy process	Non-computer-assisted personal interview	To test for support for multiple prioritisation criteria
Lim *et al.* (2012)	ROK	800 (public)	DCE	Internet survey	To test for support for multiple prioritisation criteria
Linley and Hughes (2013)	UK	4,118 (public)	Budget allocation	Internet survey	To test for support for multiple prioritisation criteria
McHugh *et al.* (2015)	UK	61 ('data-rich' individuals) [b]	Q method	Non-computer-assisted personal interview	Qualitative examination of societal perspectives in relation to end-of-life prioritisation
Pennington *et al.* (2015)	Multiple	17,657 (public)	WTP	Internet survey	To compare WTP for different types of QALY gain
Pinto-Prades *et al.* (2014)	SPA	813 (public)	WTP; PTO	Computer-assisted personal interview	To test for support for end-of-life prioritisation and to compare support for life extensions vs. quality-of-life improvements
Richardson *et al.* (2012)	AUS	544 (public)	Other	Multiple modes: Internet survey and self-completion survey (postal)	To test a technique for measuring support for health-maximisation and health sharing
Rowen *et al.* (2016a)	UK	3,669 (public)	DCE	Internet survey	To test for support for multiple prioritisation criteria
Rowen *et al.* (2016b)	UK	371 (public)	Choice	Multiple modes: Internet survey and	To test for framing and mode of administration effects in the elicitation of preferences regarding burden of illness

Authors (date)	Country	Sample size (type)	Method [a]	Mode of administration	Summary of primary study objective(s)
				non-computer-assisted personal interview	
Shah *et al.* (2014)	UK	50 (public)	Choice	Non-computer-assisted personal interview	To test for support for end-of-life prioritisation
Shah *et al.* (2015a)	UK	3,969 (public)	DCE	Internet survey	To test for support for end-of-life prioritisation
Shiroiwa *et al.* (2010)	Multiple	5,620 (public)	WTP	Internet survey	To obtain the monetary value of a QALY (in six countries)
Shiroiwa *et al.* (2013)	JPN	2,283 (public)	WTP	Internet survey	To obtain the monetary value of a QALY
Skedgel *et al.* (2015)	CAN	595 (public); 61 (decision-makers)	DCE	Internet survey	To test for support for multiple prioritisation criteria
Stahl *et al.* (2008)	USA	623 (public)	Choice	Internet survey	To test for support for multiple prioritisation criteria
Stolk *et al.* (2005)	NLD	65 (students, researchers, health policy makers)	Choice	Non-computer-assisted personal interview	To test for support for multiple approaches to priority-setting
Wouters *et al.* (2017)	NLD	46 (public, individuals with experience of cancer)	Q method	Multiple modes: Non-computer-assisted personal interview and focus group	Qualitative examination of societal perspectives in relation to end-of-life prioritisation

[a] Choice = choice exercise that did not include design or analysis methods associated with the DCE technique; DCE = discrete choice experiment; PTO = person trade-off; WTP = willingness-to-pay

[b] Made up of 59 data-rich individuals with different types of experiences or expertise in end-of-life in a professional and/or personal capacity (e.g. researchers, pharmaceutical industry employees, patient group representatives, religious group representatives, clinicians, people with experience of terminal illness in family members), plus two ‘meta-respondents’ representing the views of 250 general public respondents.

Table 2. Distribution of key variables (n=20)

Variable	Freq.	%
Year of study publication		
- Prior to 2009	5	21.7%
- 2009 onwards	18	78.3%
Year of study conduct [a]		
- Prior to 2009	7	30.4%
- 2009 onwards	16	69.6%
Sample size		
- 1-99	6	26.1%
- 100-999	10	43.5%
- 1,000+	7	30.4%
Perspective		
- Own health	2	8.7%
- Social decision-maker	19	82.6%
- Both	2	8.7%
Method / preference elicitation technique		
- Discrete choice experiment	5	21.7%
- Other choice exercise	7	30.4%
- Analytic hierarchy	1	4.3%
- Budget allocation	2	8.7%
- Q methodology	2	8.7%
- Willingness-to-pay	3	13.0%
- Person trade-off and willingness-to-pay [b]	1	4.3%
- Ranking exercise and other choice exercise [c]	1	4.3%
- Other	1	4.3%
Mode of administration		
- Internet survey	11	47.8%
- Computer-assisted personal interview	2	8.7%
- Non-computer-assisted personal interview	4	17.4%
- Focus group	2	8.7%
- Self-completion paper survey (completed in group setting)	1	4.3%
- Multiple modes [d]	3	13.0%
Disease labelled?		
- No	18	78.3%
- Yes – choice between several named diseases	1	4.3%
- Yes – choice between treatments for a single named disease or disease area	4	17.4%
Shortest life expectancy presented		
- 0mths (i.e. imminent death)	4	17.4%
- 0mths < LE ≤3mths	6	26.1%
- 3mths < LE ≤ 12mths	6	26.1%
- 12mths < LE	4	17.4%
- No length specified	3	13.0%
Possible to express indifference?		
- Yes	13	56.5%
- No	9	39.1%
- Not reported / unclear	1	4.3%
Visual aids used?		
- Yes [e]	10	43.5%
- No	13	56.5%
Strength of preference examined at the individual respondent level?		
- Yes	12	52.2%
- No	10	43.5%
- Not reported / unclear	1	4.3%
Qualitative data or explanations for choices sought?		
- Yes	9	39.1%
- No / not reported	14	60.9%
Impact of background characteristics		
- At least one characteristic found to be associated with preferences	6	26.1%
- No characteristics found to be associated with preferences	8	34.8%
- Not reported	9	39.1%
Any reference to age-related preferences?		
- Yes	15	65.2%
- No	8	34.8%
Any reference to time-related preferences?		
- Yes – an attempt was made to control for or analyse time-related preferences	4	17.4%
- Yes – time-related preferences were mentioned but not controlled for	3	13.0%
- No	16	69.5%
Overall finding: end-of-life vs. non-end-of-life		

Variable	Freq.	%
- Consistent with an end-of-life premium	8	34.8%
- Not consistent with an end-of-life premium	11	47.8%
- Mixed or inconclusive evidence	4	17.4%
Overall finding: quality-of-life-improving vs. life-extending end-of-life treatments		
- Quality-of-life improvement preferred	2	8.7%
- Life extension preferred	1	4.3%
- Mixed or inconclusive evidence	2	8.7%
- Not examined / reported	18	78.3%

[a] Not always reported – in some cases this was inferred based on the year of study publication; in other cases clarification was sought by means of personal communication with authors

[b] Separate methods – all respondents completed tasks using both methods

[c] Hybrid method – all respondents were asked first to choose which of six patient groups to treat, and then to rank the six patient groups in order of preference

[d] Internet survey and self-completion paper survey; internet survey and non-computer-assisted personal interview; non-computer-assisted personal interview and focus group

[e] One study is counted as a study that used visual aids on the basis that visual aids were used in the majority of study arms (and for the majority of respondents)

Table 3. Distribution of selected variables, by overall study finding

Variable	Evidence consistent with an end-of-life premium	Evidence not consistent with an end-of-life premium
Country		
- UK	2	5
- Europe (non-UK)	2	3
- Rest of the world [a]	4	3
Year of study conduct		
- Prior to 2009	6	8
- 2009 onwards	2	3
Sample size		
- 1-99	1	3
- 100-999	4	4
- 1,000+	3	4
Method [b]		
- DCE	2	2
- Other choice exercise	2	4
- Willingness-to-pay	3	1
- Other	2	4
Mode of administration [c]		
- Internet survey	5	7
- Other	3	5
Shortest life expectancy presented		
- 0mths ≤ LE ≤ 3mths	5	2
- 3mths < LE	3	7
- No length specified	1	1
Possible to express indifference?		
- Yes	6	5
- No or not reported	2	6
Visual aids used? [d]		
- Yes	5	3
- No or not reported	3	9

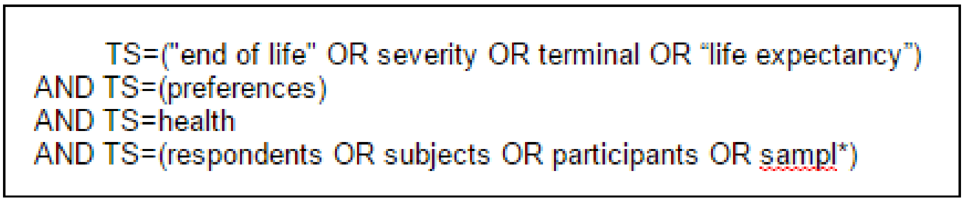
[a] Includes a multi-country study conducted in Australia, Japan, South Korea, Taiwan, UK and USA. Counted as a 'Rest of the world' study because the UK sample comprised less than 20% of the total sample.

[b] Study combining person trade-off and willingness-to-pay methods counted as two studies since separate results are reported for both. Study combining ranking exercise and other choice exercise counted as one study since this is considered to be a single hybrid method.

[c] Study combining internet survey and non-computer-assisted personal interview modes of administration counted as two studies since separate results are reported for both.

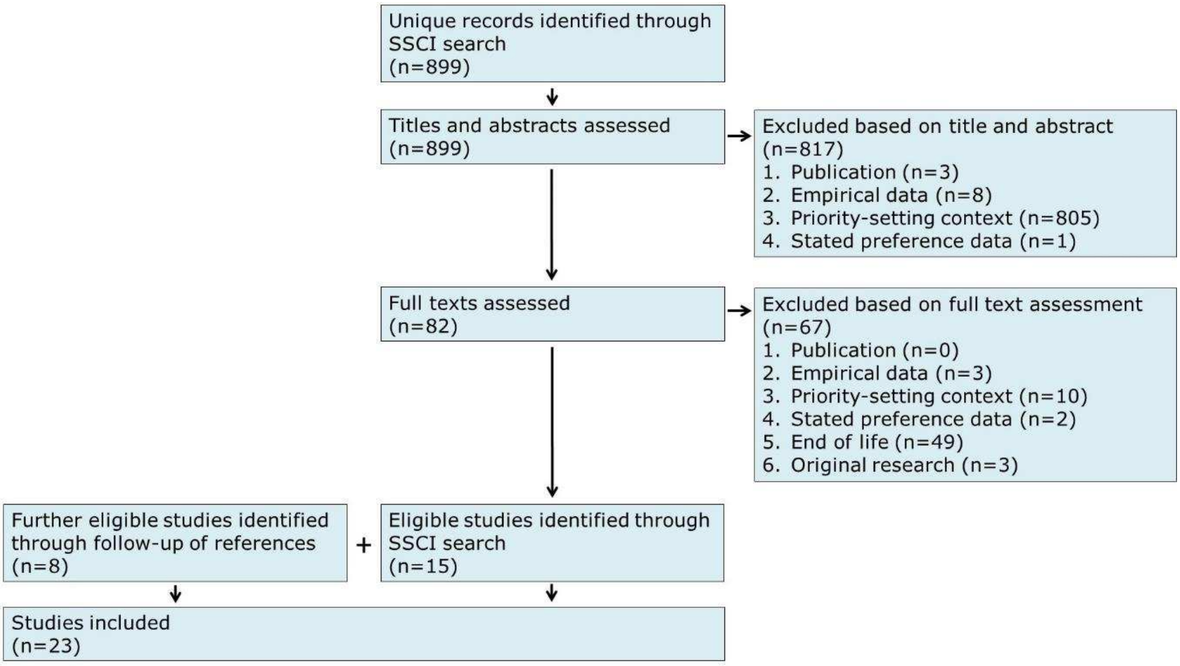
[d] Study combining visual aid and no visual aid arms counted as two studies since separate results are reported for both.

Box 1. Final search strategy



```
        TS=("end of life" OR severity OR terminal OR “life expectancy”)
AND TS=(preferences)
AND TS=health
AND TS=(respondents OR subjects OR participants OR sampl*)
```

Figure 1. Flow chart of search results



Record	**Abel Olsen, J., 2013. Priority preferences: "end of life" does not matter, but total life does. Value in Health 16, 1063-1066.**
Year of publication	2013
Year of study conduct	2010
Country or countries of origin of data	Norway
Sample size	503
Type of sample	Public
Sample recruitment process	Recruited by agency
Criteria for excluding respondents and/or observations reported?	No
Mode of administration	Internet survey
Summary of primary study objective(s)	To test for support for end of life prioritisation and the fair innings approach
Was end of life (or a related term) mentioned explicitly in the study objectives?	Yes
Pilot reported?	No
Preference elicitation technique	Other choice exercise
Perspective	Social decision maker
End of life definition	Remaining lifetime without treatment
Life expectancy without treatment attribute levels	1yr, 3yrs, 10yrs
Life expectancy gain from treatment attribute levels	1mth, 3mths, 1yr, 3yrs
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No
What were respondents choosing between (or choosing to do)?	Which of two patients to treat
Was it possible to express indifference?	Yes – following an initial forced choice without an indifference option, respondents were asked to specify how large a gain their less preferred patient would need in order for the two patients to have equal priority (hence, although respondents were never given an explicit indifference option to choose, they were able to express indifference by specifying a size of gain for their less preferred patient that was no different from that indicated in the initial forced choice question)
Were visual aids used?	No

Record	**Abel Olsen, J., 2013. Priority preferences: "end of life" does not matter, but total life does. Value in Health 16, 1063-1066.**
Strength of preference examined at the individual respondent level?	Yes – using benefit trade-off type approach
Number of tasks completed by each respondent	4
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence not consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	Evidence of support for the fair innings approach
Other factors examined	Fair innings approach, health gain
Impact of background characteristics reported?	No
Were qualitative data or explanatory factors sought?	Yes – respondents were asked which factor was most important to them when answering the questions
Was any reference made to age-related preferences?	Yes – evidence of a desire to reduce inequalities in age at death
Was any reference made to time-related preferences?	No

Record	**Baker, R., Bateman, I., Donaldson, C., Jones-Lee, M., Lancsar, E., Loomes, G., Mason, H., Odejar, M., Pinto Prades, J.L., Robinson, A., Ryan, M., Shackley, P., Smith, R., Sugden, R. and Wildman, J., 2010a. Weighting and valuing quality-adjusted life-years using stated preference methods: preliminary results from the Social Value of a QALY Project. Health Technology Assessment 14(27).**
Year of publication	2010
Year of study conduct	2007
Country or countries of origin of data	UK
Sample size	587
Type of sample	Public
Sample recruitment process	Recruited by agency
Criteria for excluding respondents and/or observations reported?	No
Mode of administration	CAPI
Summary of primary study objective(s)	To test for support for multiple prioritisation criteria
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	Yes
Preference elicitation technique	Discrete choice experiment
Perspective	Social decision maker
End of life definition	Age at onset and age at death if untreated were included as variables; when age at onset = age at death if untreated, the profile describes an imminent death scenario where any treatment is life-saving/extending
Life expectancy without treatment attribute levels	0yrs, 9yrs, 10yrs, various levels > 10yrs (not presented explicitly, but can be calculated indirectly by subtracting age at onset from age at death if untreated)
Life expectancy gain from treatment attribute levels	0yrs, 1yr, 5yrs, 10yrs, 20yrs, 40yrs, 60yrs, 79yrs
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No – when age at onset = age at death if untreated, all treatments are necessarily life-extending
What were respondents choosing between (or choosing to do)?	Which of two patient groups to treat
Was it possible to express indifference?	No

Record	**Baker, R., Bateman, I., Donaldson, C., Jones-Lee, M., Lancsar, E., Loomes, G., Mason, H., Odejar, M., Pinto Prades, J.L., Robinson, A., Ryan, M., Shackley, P., Smith, R., Sugden, R. and Wildman, J., 2010a. Weighting and valuing quality-adjusted life-years using stated preference methods: preliminary results from the Social Value of a QALY Project. Health Technology Assessment 14(27).**
Were visual aids used?	Yes
Strength of preference examined at the individual respondent level?	No
Number of tasks completed by each respondent	8 (+6 tasks using a different method that did not examine end of life, as well as attitudinal questions)
Time taken to complete survey reported?	Yes – 41 min (average)
Summary of finding: end of life vs. non-end of life	Mixed or inconclusive evidence
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	In ranking exercise (n=19) conducted in preliminary study, life expectancy without treatment was ranked third out of 10 priority-setting attributes (below quality of life without treatment but above all patient characteristics, e.g. age, lifestyle); age and severity did not have a strong impact on choices over and above QALY gains
Other factors examined	Age at onset, age at death, life expectancy gain, quality of life without treatment, quality of life gain
Impact of background characteristics reported?	No
Were qualitative data or explanatory factors sought?	Yes – in preliminary work (but end of life was not a specific topic of discussion)
Was any reference made to age-related preferences?	Yes – evidence of preference for life-saving treatments for 10 year old patients but not for other patients of other ages
Was any reference made to time-related preferences?	No

Record	**Dolan, P. and Cookson, R., 2000. A qualitative study of the extent to which health gain matters when choosing between groups of patients. Health Policy, 51, 19-30.**
Year of publication	2000
Year of study conduct	Not reported
Country or countries of origin of data	UK
Sample size	60
Type of sample	Public
Sample recruitment process	Random postal invitations
Criteria for excluding respondents and/or observations reported?	No exclusions
Mode of administration	Focus group
Summary of primary study objective(s)	Qualitative examination of support for multiple prioritisation criteria
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	No
Preference elicitation technique	Other choice exercise
Perspective	Social decision maker (operationalised using a veil of ignorance condition for half of the respondents)
End of life definition	Life expectancy without treatment
Life expectancy without treatment attribute levels	0yrs, 5yrs, 10yrs, 30yrs (but the sole end of life vs. non-end of life question involved a choice between patients with life expectancies of 10yrs and 30yrs, respectively)
Life expectancy gain from treatment attribute levels	5yrs, 10yrs, 15yrs, 20yrs (but in the sole end of life vs. non-end of life question, life expectancy gain was 10yrs for both candidate recipient groups)
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No – quality of life was examined but in separate questions
What were respondents choosing between (or choosing to do)?	Which of two patient groups to treat (with the gain attribute then increased/reduced incrementally)
Was it possible to express indifference?	Yes – a ‘same priority’ option was available
Were visual aids used?	No

Record	**Dolan, P. and Cookson, R., 2000. A qualitative study of the extent to which health gain matters when choosing between groups of patients. Health Policy, 51, 19-30.**
Strength of preference examined at the individual respondent level?	Yes – attribute levels were varied incrementally
Number of tasks completed by each respondent	6 (+initial discussion and questionnaire on health care priority-setting in general)
Time taken to complete survey reported?	Yes – meeting lasted for two hours
Summary of finding: end of life vs. non-end of life	Mixed or inconclusive evidence
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	Veil of ignorance perspective (vs. social decision maker) had no discernible impact; authors conclude from data that "equality of access should prevail over the maximisation of benefits" (p.19)
Other factors examined	Quality of life without treatment, quality of life with treatment; other factors were mentioned by respondents but these were either irrelevant or factors that they were not supposed to have considered (e.g. costs)
Impact of background characteristics reported?	Yes – none found to influence propensity to favour treating end of life patients
Were qualitative data or explanatory factors sought?	Yes – study was predominantly a qualitative exercise
Was any reference made to age-related preferences?	Yes – but age was intended to be an irrelevant factor
Was any reference made to time-related preferences?	No

Record	**Dolan, P. and Shaw, R., 2004. A note on a discussion group study of public preferences regarding priorities in the allocation of donor kidneys. Health Policy, 68, 31-36.**
Year of publication	2004
Year of study conduct	Not reported
Country or countries of origin of data	UK
Sample size	23
Type of sample	Public
Sample recruitment process	Recruited by agency
Criteria for excluding respondents and/or observations reported?	No
Mode of administration	Focus group
Summary of primary study objective(s)	To test for support for multiple prioritisation criteria
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	No
Preference elicitation technique	Other choice exercise
Perspective	Social decision maker
End of life definition	Life expectancy without transplant
Life expectancy without treatment attribute levels	1yr, 4yrs, 7yrs, 10yrs, 13yrs, 16yrs
Life expectancy gain from treatment attribute levels	5yrs, 10yrs, 15yrs, 20yrs, 25yrs, 30yrs
Was disease labelled or named?	Yes – kidney failure
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No
What were respondents choosing between (or choosing to do)?	Which of six patients should receive a kidney transplant
Was it possible to express indifference?	No
Were visual aids used?	No
Strength of preference examined at the individual respondent level?	No

Record	**Dolan, P. and Shaw, R., 2004. A note on a discussion group study of public preferences regarding priorities in the allocation of donor kidneys. Health Policy, 68, 31-36.**
Number of tasks completed by each respondent	3
Time taken to complete survey reported?	Yes – two meetings, each of which lasted for two hours
Summary of finding: end of life vs. non-end of life	Evidence not consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	Benefit from transplantation was the most important criterion overall; some participants chose to prioritise those with dependants
Other factors examined	Other factors mentioned by participants: age, family responsibilities, waiting time, cause, whether a re-transplantation or not
Impact of background characteristics reported?	No
Were qualitative data or explanatory factors sought?	Yes – study was predominantly a qualitative exercise
Was any reference made to age-related preferences?	Yes – the participants who had chosen to treat the patient with shortest life expectancy without transplant did not continue to do so when it was revealed that this patient was the oldest of the six candidate recipients
Was any reference made to time-related preferences?	No

Record	**Dolan, P. and Tsuchiya, A., 2005. Health priorities and public preferences: the relative importance of past health experience and future health prospects. Journal of Health Economics, 24, 703-714.**
Year of publication	2005
Year of study conduct	2002
Country or countries of origin of data	UK
Sample size	100
Type of sample	Public
Sample recruitment process	Postal invitation
Criteria for excluding respondents and/or observations reported?	Yes – excluded respondents who did not complete all of the tasks
Mode of administration	Self-completion paper survey (administered in group setting)
Summary of primary study objective(s)	To compare support for prioritisation according to age vs. prioritisation according to severity/life expectancy
Was end of life (or a related term) mentioned explicitly in the study objectives?	Yes
Pilot reported?	No
Preference elicitation technique	Ranking exercise and other choice exercise
Perspective	Social decision maker
End of life definition	Future years without treatment
Life expectancy without treatment attribute levels	1yr, 6yrs
Life expectancy gain from treatment attribute levels	3yrs
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No – a question examining quality of life improvement was included, but the size of the life extension was fixed
What were respondents choosing between (or choosing to do)?	Which of six patient groups to treat; then to rank the six patient groups
Was it possible to express indifference?	No
Were visual aids used?	No
Strength of preference examined at the individual respondent level?	No

Record	**Dolan, P. and Tsuchiya, A., 2005. Health priorities and public preferences: the relative importance of past health experience and future health prospects. Journal of Health Economics, 24, 703-714.**
Number of tasks completed by each respondent	4
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence not consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	Future health (quality of life without treatment) did not have a statistically significant effect on choices made, whereas past years (age) had a strong effect
Other factors examined	Past age, past health, quality of life without treatment
Impact of background characteristics reported?	Yes – age, education and employment status were all found to have statistically significant interactions with life expectancy without treatment
Were qualitative data or explanatory factors sought?	No – discussions were not recorded as it was not intended to be a qualitative study
Was any reference made to age-related preferences?	Yes – younger patient groups were always chosen over older ones
Was any reference made to time-related preferences?	No

Record	**Lim, M.K., Bae, E.Y., Choi, S.E., Lee, E.K. and Lee, T.J., 2012. Eliciting public preference for health-care resource allocation in South Korea. Value in Health, 15, S91-S94.**
Year of publication	2012
Year of study conduct	2010
Country or countries of origin of data	Korea
Sample size	800
Type of sample	Public
Sample recruitment process	Recruited by agency
Criteria for excluding respondents and/or observations reported?	Yes – excluded multiple responses from the same IP address
Mode of administration	Internet survey
Summary of primary study objective(s)	To test for support for multiple prioritisation criteria
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	No (but focus groups were conducted, in part to inform the selection of attributes in the internet survey)
Preference elicitation technique	Discrete choice experiment
Perspective	Social decision maker
End of life definition	Life expectancy without treatment
Life expectancy without treatment attribute levels	1yr, 5yrs, 10yrs, 20yrs, 25yrs, 35yrs
Life expectancy gain from treatment attribute levels	0yrs, 1yr, 5yrs, 10yrs, 20yrs, 30yrs
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No
What were respondents choosing between (or choosing to do)?	Which of two patients to treat
Was it possible to express indifference?	Not reported
Were visual aids used?	Yes
Strength of preference examined at the individual respondent level?	No

Record	**Lim, M.K., Bae, E.Y., Choi, S.E., Lee, E.K. and Lee, T.J., 2012. Eliciting public preference for health-care resource allocation in South Korea. Value in Health, 15, S91-S94.**
Number of tasks completed by each respondent	17
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	All attributes had statistically significant coefficients with signs that were consistent with the authors' expectations (QALY gain – positive; quality of life before treatment – negative; patient's household income – negative)
Other factors examined	QALY gain; quality of life before treatment; household income group
Impact of background characteristics reported?	No
Were qualitative data or explanatory factors sought?	Yes – using focus groups (but end of life was not a specific topic for discussion)
Was any reference made to age-related preferences?	No
Was any reference made to time-related preferences?	No

Record	**Linley, W.G. and Hughes, D.A., 2013. Societal views on NICE, Cancer drugs fund and value-based pricing criteria for prioritising medicines: a cross-sectional survey of 4118 adults in Great Britain. Health Economics, 22, 948-964.**
Year of publication	2013
Year of study conduct	2011
Country or countries of origin of data	UK
Sample size	4,118
Type of sample	Public
Sample recruitment process	Recruited by agency
Criteria for excluding respondents and/or observations reported?	No
Mode of administration	Internet survey
Summary of primary study objective(s)	To test for support for multiple prioritisation criteria
Was end of life (or a related term) mentioned explicitly in the study objectives?	No – end of life was one of many prioritisation criteria examined
Pilot reported?	Yes
Preference elicitation technique	Budget allocation
Perspective	Social decision maker
End of life definition	Fatal disease that leads to death in 18 months without treatment
Life expectancy without treatment attribute levels	18mths, 60mths
Life expectancy gain from treatment attribute levels	3mths, 6mths
Was disease labelled or named?	No (but preferences regarding 'fatal cancer' were examined in a separate question)
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No
What were respondents choosing between (or choosing to do)?	To allocate a fixed budget between two groups of patients
Was it possible to express indifference?	Yes – a 50:50 split option was available
Were visual aids used?	No
Strength of preference examined at the individual respondent level?	Yes – respondents could choose from 11 different distributions of funding, and further 'health gain trade-off' and 'cost trade-off' approaches were also used

Record	**Linley, W.G. and Hughes, D.A., 2013. Societal views on NICE, Cancer drugs fund and value-based pricing criteria for prioritising medicines: a cross-sectional survey of 4118 adults in Great Britain. Health Economics, 22, 948-964.**
Number of tasks completed by each respondent	18 (of which two examined end of life explicitly)
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence not consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	Evidence of support for prioritising treatment of severe illness, but not for prioritising treatment of cancer specifically
Other factors examined	Health gain; many others examined separately from end of life
Impact of background characteristics reported?	Yes – none found to influence propensity to favour treating end of life patients
Were qualitative data or explanatory factors sought?	No / not reported
Was any reference made to age-related preferences?	Yes – respondents did not support giving priority to the treatment of children overall (questions about children were separate from those about end of life)
Was any reference made to time-related preferences?	No

Record	**McHugh, N., Baker, R.M., Mason, H., Williamson, L., van Exec, J., Deogaonkar, R., Collins, M. and Donaldson, C., 2015. Extending life for people with a terminal illness: a moral right and an expensive death? Exploring societal perspectives. BMC Medical Ethics, 16(14).**
Year of publication	2015
Year of study conduct	Not reported
Country or countries of origin of data	UK
Sample size	61
Type of sample	Individuals with different types of experiences or expertise in end of life in a professional or personal capacity (e.g. researchers, clinicians, people with experience of terminal illness)
Sample recruitment process	Purposive (to identify data-rich respondents)
Criteria for excluding respondents and/or observations reported?	No
Mode of administration	Non-computer-assisted personal interview
Summary of primary study objective(s)	Qualitative examination of societal perspectives in relation to end of life prioritisation
Was end of life (or a related term) mentioned explicitly in the study objectives?	Yes
Pilot reported?	Yes
Preference elicitation technique	Q methodology (technique that combines card sort and ranking exercise)
Perspective	Social decision maker (though a minority of statements were framed using an own health perspective)
End of life definition	Described in multiple ways (e.g. 'terminally ill', 'die soon')
Life expectancy without treatment attribute levels	N/A
Life expectancy gain from treatment attribute levels	N/A
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	Yes
What were respondents choosing between (or choosing to do)?	Rank statements according to how much they agreed or disagreed with them
Was it possible to express indifference?	Yes – in the grid ranging from -5 (most disagree) to +5 (most agree), respondents were able to place statements in the position marked 0
Were visual aids used?	No

Record	**McHugh, N., Baker, R.M., Mason, H., Williamson, L., van Exec, J., Deogaonkar, R., Collins, M. and Donaldson, C., 2015. Extending life for people with a terminal illness: a moral right and an expensive death? Exploring societal perspectives. BMC Medical Ethics, 16(14).**
Strength of preference examined at the individual respondent level?	Yes – strength of preference indicated by position in which statements were placed on the grid
Number of tasks completed by each respondent	1 (comprising sorting and placing of 49 statements on grid)
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Mixed or inconclusive evidence
Summary of finding: quality of life improvement vs. life extension	Mixed or inconclusive evidence
Other results of potential interest	Three shared accounts identified: (1) A population perspective – value for money, no special cases; (2) Life is precious – valuing life-extensions and patient choice; (3) Valuing wider benefits and opportunity cost – the quality of life and death
Other factors examined	Alternative perspectives and approaches to resource allocation – e.g. health-maximisation, provision of treatments to patients with non-terminal conditions
Impact of background characteristics reported?	Yes (though authors warn about making generalisations based on qualitative samples) – e.g. no academics helped to define the shared account most closely related to an end of life premium
Were qualitative data or explanatory factors sought?	Yes – study was in part a qualitative exercise
Was any reference made to age-related preferences?	Yes – e.g. one statement was worded: “I think life-extending treatments for people who are terminally ill are of less value as people get older”
Was any reference made to time-related preferences?	No reference to time discounting *per se*, but several statements referred to the value of time – e.g. “It is important to give a dying person and their family time to prepare for their death, put their affairs in order, make peace and say goodbyes”

Record	**Pennington, M., Baker, R., Brouwer, W., Mason, H., Hansen, D. G., Robinson, A. and Donaldson, C., 2015. Comparing WTP values of different types of QALY gain elicited from the general public. Health Economics, 24, 280-293.**
Year of publication	2015
Year of study conduct	2009-2010
Country or countries of origin of data	Denmark, France, Hungary, Netherlands, Norway, Poland, Spain, Sweden, UK
Sample size	17,657
Type of sample	Public
Sample recruitment process	Internet panel
Criteria for excluding respondents and/or observations reported?	Yes – excluded protest responders; respondents who expected to live for less than 6yrs were directed to a different questionnaire (not reported); impact of other exclusions reported in sensitivity analysis
Mode of administration	Internet survey
Summary of primary study objective(s)	To compare willingness to pay for different types of QALY gain
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	Yes
Preference elicitation technique	Willingness to pay
Perspective	Own health
End of life definition	"Imminent, premature death from a life threatening disease" (at least six years before respondent's self-reported expected end of life
Life expectancy without treatment attribute levels	Imminent (as above), respondent’s self-reported life expectancy
Life expectancy gain from treatment attribute levels	1 QALY worth of life extension (at a quality of life level consistent with respondent’s self-reported health)
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No – quality of life was examined but in separate questions
What were respondents choosing between (or choosing to do)?	What the maximum amount they would be willing to pay for a given specific gain
Was it possible to express indifference?	Yes – respondents could provide the same willingness to pay value for multiple gains
Were visual aids used?	Yes
Strength of preference examined at the individual respondent level?	Yes – strength of preference indicated by differing willingness to pay amounts

Record	**Pennington, M., Baker, R., Brouwer, W., Mason, H., Hansen, D. G., Robinson, A. and Donaldson, C., 2015. Comparing WTP values of different types of QALY gain elicited from the general public. Health Economics, 24, 280-293.**
Number of tasks completed by each respondent	5
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	When comparing QALY gains obtained in the near future, life extensions were valued more highly then quality of life improvements; low median values for life extensions at respondents' expected end of life strongly influenced by the large number of observations at zero
Other factors examined	Avoiding quality of life loss now (over 4yrs or 10yrs); avoiding time spent in coma (intended to elicit a gain in longevity occurring in the near future)
Impact of background characteristics reported?	Yes – older age and poorer health associated with lower willingness to pay values for life extension in imminent death scenario
Were qualitative data or explanatory factors sought?	No / not reported
Was any reference made to age-related preferences?	Yes – hypothetical scenarios was based on respondents' actual ages and self-reported life expectancies
Was any reference made to time-related preferences?	Yes – authors acknowledge that gains in the future would be discounted, and that for an individual facing immediate death the normal opportunity cost considerations may not apply

Record	**Pinto-Prades, J.L., Sanchez-Martínez, F.I., Corbacho, B., Baker, R., 2014. Valuing QALYs at the end of Life. Social Science and Medicine, 113, 5-14.**
Year of publication	2014
Year of study conduct	2010
Country or countries of origin of data	Spain
Sample size	813
Type of sample	Public
Sample recruitment process	Door-knock
Criteria for excluding respondents and/or observations reported?	Yes – excluded protest responders in the willingness to pay tasks
Mode of administration	Computer-assisted personal interview
Summary of primary study objective(s)	To test for support for end of life prioritisation
Was end of life (or a related term) mentioned explicitly in the study objectives?	Yes
Pilot reported?	Yes
Preference elicitation technique	Willingness to pay and person trade-off
Perspective	Both – own health (willingness to pay tasks); social decision maker (person trade-off tasks)
End of life definition	Life expectancy without treatment
Life expectancy without treatment attribute levels	3mths, 6mths, 18mths
Life expectancy gain from treatment attribute levels	6mths, 18mths
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	Yes
What were respondents choosing between (or choosing to do)?	What the maximum amount they would be willing to pay for a 10% chance of improving their condition in a specified way (willingness to pay tasks); the number of patients treated of one type they consider equivalent to treating one patient of another type (person trade-off tasks)
Was it possible to express indifference?	Yes – respondents could provide the same willingness to pay value for multiple gains or choose an equal number of both types of patient in the person trade-off task
Were visual aids used?	Yes

Record	**Pinto-Prades, J.L., Sanchez-Martínez, F.I., Corbacho, B., Baker, R., 2014. Valuing QALYs at the end of Life. Social Science and Medicine, 113, 5-14.**
Strength of preference examined at the individual respondent level?	Yes – strength of preference indicated by differing willingness to pay amounts and levels of trade-off
Number of tasks completed by each respondent	6
Time taken to complete survey reported?	Yes – 21 minutes on average
Summary of finding: end of life vs. non-end of life	Evidence consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Quality of life improvement preferred
Other results of potential interest	Reasonably large proportion of respondents did not give too much value to a short life extension but those who did were willing to pay quite a lot (similar split of opinion observed in PTO responses)
Other factors examined	None
Impact of background characteristics reported?	No
Were qualitative data or explanatory factors sought?	No / not reported
Was any reference made to age-related preferences?	No
Was any reference made to time-related preferences?	No

Record	**Richardson, J., Sinha, K., Iezzi, A. and Maxwell, A., 2012. Maximising health versus sharing: Measuring preferences for the allocation of the health budget. Social Science & Medicine, 75, 1351-1361.**
Year of publication	2012
Year of study conduct	2009-2010
Country or countries of origin of data	Australia
Sample size	544
Type of sample	Public
Sample recruitment process	Internet panel; targeted postal invitations (based on socioeconomic characteristics of residential postcodes)
Criteria for excluding respondents and/or observations reported?	Yes – excluded respondents whose comments or answers indicated misunderstanding
Mode of administration	Multiple modes: internet survey; self-completion paper survey (postal)
Summary of primary study objective(s)	To test a technique for measuring support for health-maximisation and health sharing
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	No
Preference elicitation technique	Novel cross between a discrete choice and budget allocation exercise
Perspective	Social decision maker
End of life definition	Immediate death without treatment
Life expectancy without treatment attribute levels	Multiples of 4yrs and 6yrs
Life expectancy gain from treatment attribute levels	4yrs, 6yrs, 8yrs, 12yrs
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No
What were respondents choosing between (or choosing to do)?	Which of four patients to give a life extension to
Was it possible to express indifference?	No
Were visual aids used?	Yes
Strength of preference examined at the individual respondent level?	Not reported / unclear

Record	**Richardson, J., Sinha, K., Iezzi, A. and Maxwell, A., 2012. Maximising health versus sharing: Measuring preferences for the allocation of the health budget. Social Science & Medicine, 75, 1351-1361.**
Number of tasks completed by each respondent	1 (comprising 18 to 29 iterations)
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Mixed or inconclusive evidence
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	Results indicate that respondents were primarily concerned with outcome egalitarianism (as opposed to maximising health outcomes)
Other factors examined	Sharing / outcome egalitarianism
Impact of background characteristics reported?	Yes – none found to influence propensity to favour treating end of life patients
Were qualitative data or explanatory factors sought?	No / not reported
Was any reference made to age-related preferences?	No – but all patients start at the same age (25yrs), so the results could be interpreted in terms of desire to equalise expected age at death
Was any reference made to time-related preferences?	Yes – authors acknowledge that there may be some variation from the orthodox economic prediction if time discounting is taken into account

Record	**Rowen, D., Brazier, J., Mukuria, C., Keetharuth, A, Risa Hole, A., Tsuchiya, A., Whyte, S. and Shackley, P., 2016a. Eliciting societal preferences for weighting QALYs for burden of illness and end of life. Medical Decision Making, 36, 210-222.**
Year of publication	2015
Year of study conduct	Not reported
Country or countries of origin of data	UK
Sample size	3,669
Type of sample	Public
Sample recruitment process	Internet panel
Criteria for excluding respondents and/or observations reported?	No exclusions
Mode of administration	Internet survey
Summary of primary study objective(s)	To test for support for multiple prioritisation criteria
Was end of life (or a related term) mentioned explicitly in the study objectives?	Yes
Pilot reported?	Yes
Preference elicitation technique	Discrete choice experiment
Perspective	Social decision maker
End of life definition	Life expectancy without treatment; dummy variable in the modelling representing the cut-offs associated with the NICE criteria
Life expectancy without treatment attribute levels	3mths, 6mths, 9mths, 1yr, 2yrs, 5yrs, 10yrs, 30yrs, 60yrs
Life expectancy gain from treatment attribute levels	0mths, 1mth, 3mths, 6mths, 9mths, 1yr, 3yrs, 10yrs, 60yrs
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No
What were respondents choosing between (or choosing to do)?	Which of two patient groups to treat
Was it possible to express indifference?	No
Were visual aids used?	Yes
Strength of preference examined at the individual respondent level?	No

Record	**Rowen, D., Brazier, J., Mukuria, C., Keetharuth, A, Risa Hole, A., Tsuchiya, A., Whyte, S. and Shackley, P., 2016a. Eliciting societal preferences for weighting QALYs for burden of illness and end of life. Medical Decision Making, 36, 210-222.**
Number of tasks completed by each respondent	10 (+further attitudinal questions)
Time taken to complete survey reported?	Yes – 21 minutes on average
Summary of finding: end of life vs. non-end of life	Evidence consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	Preference for larger QALY gains, but at a diminishing rate; some support for prioritising those with higher burden of illness, though not robust
Other factors examined	QALY gain, burden of illness
Impact of background characteristics reported?	No
Were qualitative data or explanatory factors sought?	Yes – in piloting and via attitudinal questions
Was any reference made to age-related preferences?	No – age attribute was purposely omitted
Was any reference made to time-related preferences?	No

Record	**Rowen, D., Brazier, J., Keetharuth, A., Tsuchiya, A. and Mukuria, C., 2016b. Comparison of modes of administration and alternative formats for eliciting societal preferences for burden of illness. Applied Health Economics and Health Policy, 14, 89-104.**
Year of publication	2016
Year of study conduct	Not reported
Country or countries of origin of data	UK
Sample size	371
Type of sample	Public
Sample recruitment process	Door-knock; internet panel
Criteria for excluding respondents and/or observations reported?	No exclusions
Mode of administration	Multiple modes: non-computer-assisted personal interview (except in some arms where the introductory video was shown on a computer); internet survey
Summary of primary study objective(s)	To test for framing and mode of administration effects in the elicitation of preferences regarding burden of illness [a]
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	No
Preference elicitation technique	Other choice exercise
Perspective	Social decision maker
End of life definition	Life expectancy without treatment / due to condition
Life expectancy without treatment attribute levels	5yrs, 10yrs, 15yrs (but the sole end of life vs. non-end of life question involved a choice between patients with life expectancies of 5yrs and 10yrs, respectively)
Life expectancy gain from treatment attribute levels	0yrs, 1yr, 2yrs (but in the sole end of life vs. non-end of life question, life expectancy gain was 1yr for both candidate recipient groups)
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	Yes
What were respondents choosing between (or choosing to do)?	Which of two patient groups to treat
Was it possible to express indifference?	No
Were visual aids used?	Yes (in four of six arms; n=240); no (in two of six arms; n=131)

Record	**Rowen, D., Brazier, J., Keetharuth, A., Tsuchiya, A. and Mukuria, C., 2016b. Comparison of modes of administration and alternative formats for eliciting societal preferences for burden of illness. Applied Health Economics and Health Policy, 14, 89-104.**
Strength of preference examined at the individual respondent level?	No
Number of tasks completed by each respondent	9 (2 of which were practice tasks, but were reported in full by authors)
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence not consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported (two questions involved choices between quality of life improvements and life extensions, but life expectancy without treatment was set to 10/15 years so is deemed not to describe an end of life context)
Other results of potential interest	Responses were affected by mode of administration but not by question wording or use of visual aids
Other factors examined	QALY gain (size and type); burden of illness
Impact of background characteristics reported?	No – not for question of relevance to end of life (for other questions, few sociodemographic variables were significant)
Were qualitative data or explanatory factors sought?	No – follow-up questions were asked but these focused on framing issues and task understanding rather than on reasons for choices
Was any reference made to age-related preferences?	No
Was any reference made to time-related preferences?	No

[a] The only task in this study relevant to the research question underpinning the literature review was labelled as a 'practice question'. However, in the paper the authors do not treat the practice question as any less valid or reliable than the main (non-practice) questions, and present a full analysis of the responses to the practice questions. A notable feature of the practice questions in this study was that respondents were, in effect, asked to reconsider and confirm their responses. This suggests that the responses should not be interpreted as constituting lower quality data than the responses to the main questions. The decision to include this study in the review was informed by a discussion with one of the study authors (Tsuchiya, A., personal communication, 20 Sep 201

Record	**Shah, K.K., Tsuchiya, A. and Wailoo, A.J., 2014. Valuing health at the end of life: an empirical study of public preferences. European Journal of Health Economics, 15, 389-399.**
Year of publication	2014
Year of study conduct	2011
Country or countries of origin of data	UK
Sample size	50
Type of sample	Public
Sample recruitment process	Door-knock
Criteria for excluding respondents and/or observations reported?	No
Mode of administration	Non-computer-assisted personal interview
Summary of primary study objective(s)	To test for support for end of life prioritisation
Was end of life (or a related term) mentioned explicitly in the study objectives?	Yes
Pilot reported?	Yes
Preference elicitation technique	Other choice exercise
Perspective	Social decision maker
End of life definition	Life expectancy without treatment
Life expectancy without treatment attribute levels	1yr, 10yrs
Life expectancy gain from treatment attribute levels	6mths, 1yr
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	Yes
What were respondents choosing between (or choosing to do)?	Which patient to treat
Was it possible to express indifference?	Yes – an 'I have no preference' option was available
Were visual aids used?	Yes
Strength of preference examined at the individual respondent level?	No

Record	**Shah, K.K., Tsuchiya, A. and Wailoo, A.J., 2014. Valuing health at the end of life: an empirical study of public preferences. European Journal of Health Economics, 15, 389-399.**
Number of tasks completed by each respondent	6
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Quality of life improvement preferred
Other results of potential interest	No evidence that age- or time-related preferences are motivating factors for choosing to treat end of life patient; no evidence that concern about the life stage of end of life patients is a motivating factor for preferring either life-extending or quality of life-improving treatments for those patients
Other factors examined	Age, time preference
Impact of background characteristics reported?	No
Were qualitative data or explanatory factors sought?	Yes – respondents indicated the reasons for their choices by choosing from a list
Was any reference made to age-related preferences?	Yes – no evidence that concern about age is a motivating factor for choosing to treat end of life patient
Was any reference made to time-related preferences?	Yes – one task involved choosing between a patient who had known their prognosis for some time and another who had only just learned their prognosis (life expectancy without treatment was the same for both)

Record	**Shah, K.K., Tsuchiya, A. and Wailoo, A.J., 2015a. Valuing health at the end of life: a stated preference discrete choice experiment. Social Science & Medicine 124, 48-56.**
Year of publication	2015
Year of study conduct	2011
Country or countries of origin of data	UK
Sample size	3,969
Type of sample	Public
Sample recruitment process	Internet panel
Criteria for excluding respondents and/or observations reported?	Yes – excluded respondents who spent insufficient time completing the survey
Mode of administration	Internet survey
Summary of primary study objective(s)	To test for support for end of life prioritisation
Was end of life (or a related term) mentioned explicitly in the study objectives?	Yes
Pilot reported?	Yes
Preference elicitation technique	Discrete choice experiment
Perspective	Social decision maker
End of life definition	Life expectancy without treatment; dummy variable in the modelling representing the cut-offs associated with the NICE criteria
Life expectancy without treatment attribute levels	3mths, 12mths, 24mths, 36mths, 60mths
Life expectancy gain from treatment attribute levels	0mths, 1mth, 2mths, 3mths, 6mths, 12mths
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	Yes
What were respondents choosing between (or choosing to do)?	Which of two patients to treat
Was it possible to express indifference?	No
Were visual aids used?	Yes
Strength of preference examined at the individual respondent level?	No

Record	**Shah, K.K., Tsuchiya, A. and Wailoo, A.J., 2015a. Valuing health at the end of life: a stated preference discrete choice experiment. Social Science & Medicine 124, 48-56.**
Number of tasks completed by each respondent	10 (+2 further tasks examining the issue of preparedness)
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence not consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Life extension preferred
Other results of potential interest	Majority of respondents supported a mixture of the QALY-maximisation and priority-to-worst-off approaches to priority-setting
Other factors examined	Quality of life without treatment, preparedness
Impact of background characteristics reported?	Yes – no characteristics found to be associated with preferences
Were qualitative data or explanatory factors sought?	No / not reported
Was any reference made to age-related preferences?	No – age attribute was purposely omitted
Was any reference made to time-related preferences?	‘Time with knowledge’ attribute was examined but the results were not reported; authors note that applying a positive discount rate would likely further strengthen their finding of a lack of support for an end of life premium

Record	**Shiroiwa, T., Igarashi, A., Fukuda, T. and Ikeda, S., 2013. WTP for a QALY and health states: More money for severer health states? Cost Effectiveness and Resource Allocation, 11(22).**
Year of publication	2013
Year of study conduct	2011
Country or countries of origin of data	Japan
Sample size	2,283
Type of sample	Public
Sample recruitment process	Internet panel
Criteria for excluding respondents and/or observations reported?	Yes – recruited respondents aged 20 to 69 years only (thereby excluding individuals aged 70 years and older)
Mode of administration	Internet survey
Summary of primary study objective(s)	To obtain the monetary value of a QALY
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	No
Preference elicitation technique	Willingness to pay
Perspective	Own health
End of life definition	Life expectancy without treatment (end of life scenario 1); life-threatening situation (end of life scenario 2)
Life expectancy without treatment attribute levels	1mth
Life expectancy gain from treatment attribute levels	2mths, 4mths, 7mths, 14mths
Was disease labelled or named?	No
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No – questions examining quality of life improvement were included, but these were related to non-end of life scenarios
What were respondents choosing between (or choosing to do)?	Whether or not to pay set amounts for a given specific gain
Was it possible to express indifference?	Yes – respondents could provide the same willingness to pay value for multiple gains
Were visual aids used?	No
Strength of preference examined at the individual respondent level?	Yes – strength of preference indicated by differing willingness to pay amounts

Record	**Shiroiwa, T., Igarashi, A., Fukuda, T. and Ikeda, S., 2013. WTP for a QALY and health states: More money for severer health states? Cost Effectiveness and Resource Allocation, 11(22).**
Number of tasks completed by each respondent	1
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence not consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	Monetary value of a QALY is higher for severe health states than for mild health states
Other factors examined	Avoiding quality of life loss now (for periods lasting between 4 and 20 months)
Impact of background characteristics reported?	No – not specifically for questions of relevance to end of life (overall, willingness to pay values were significantly correlated with household income)
Were qualitative data or explanatory factors sought?	No / not reported
Was any reference made to age-related preferences?	No
Was any reference made to time-related preferences?	No

Record	**Shiroiwa, T., Sung, Y.K., Fukuda, T., Lang, H.C., Bae, S.C. and Tsutani, K., 2010. International survey on willingness-to-pay (WTP) for one additional QALY gained: what is the threshold of cost effectiveness? Health Economics, 19, 422-437.**
Year of publication	2010
Year of study conduct	2007-2008
Country or countries of origin of data	Australia, Japan, Korea, Taiwan, UK, US
Sample size	5,620
Type of sample	Public
Sample recruitment process	Internet panel
Criteria for excluding respondents and/or observations reported?	Yes – recruited respondents aged 20 to 59 years only (thereby excluding individuals aged 60 years and older)
Mode of administration	Internet survey
Summary of primary study objective(s)	To obtain the monetary value of a QALY (in six countries)
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	Yes
Preference elicitation technique	Willingness to pay
Perspective	Both – own health (end of life and non-end of life scenarios); social decision maker (end of life scenario only)
End of life definition	Serious illness that immediately threatens [your / their] life
Life expectancy without treatment attribute levels	0yrs, 5yrs
Life expectancy gain from treatment attribute levels	1yr
Was disease labelled or named?	No (but disease was described as a life-limiting illness such as metastatic cancer)
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No
What were respondents choosing between (or choosing to do)?	Whether or not to pay set amounts for a given life extension
Was it possible to express indifference?	Yes – respondents could provide the same willingness to pay value for multiple gains
Were visual aids used?	No

Record	**Shiroiwa, T., Sung, Y.K., Fukuda, T., Lang, H.C., Bae, S.C. and Tsutani, K., 2010. International survey on willingness-to-pay (WTP) for one additional QALY gained: what is the threshold of cost effectiveness? Health Economics, 19, 422-437.**
Strength of preference examined at the individual respondent level?	Yes – strength of preference indicated by differing willingness to pay amounts
Number of tasks completed by each respondent	4
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	In Japan and Korea, the highest willingness to pay values observed were for a life extension for a family member; in Australia, UK and US, the highest willingness to pay values observed were for a life extension for an unidentified member of society
Other factors examined	Willingness to pay for a life extension for a family member and for an unidentified member of society facing life-threatening illness
Impact of background characteristics reported?	Yes – respondents with high household income and education levels gave higher willingness to pay values for life extensions at the end of life
Were qualitative data or explanatory factors sought?	No / not reported
Was any reference made to age-related preferences?	No
Was any reference made to time-related preferences?	Yes – authors interpret difference between willingness to pay values in end of life and non-end of life scenarios in terms of time preference, and use the data to estimate discount rates for each country (ranging from 1.6% to 6.8%)

Record	**Skedgel, C., Wailoo, A. and Akehurst, R., 2014. Societal preferences for distributive justice in the allocation of health care resources: a latent class discrete choice experiment. Medical Decision Making, 35, 94-105.**
Year of publication	2015
Year of study conduct	2011-2012
Country or countries of origin of data	Canada
Sample size	656
Type of sample	Public, decision-makers
Sample recruitment process	Internet panel (public); flyers and email invitations (decision-makers)
Criteria for excluding respondents and/or observations reported?	No exclusions
Mode of administration	Internet survey
Summary of primary study objective(s)	To test for support for multiple prioritisation criteria
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	Yes
Preference elicitation technique	Discrete choice experiment
Perspective	Social decision maker
End of life definition	Life expectancy without treatment
Life expectancy without treatment attribute levels	1mth, 5yrs, 10yrs
Life expectancy gain from treatment attribute levels	1yr, 5yrs, 10yrs
Was disease labelled or named?	Yes – cancer
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No
What were respondents choosing between (or choosing to do)?	Which of two health programmes to allocate (all of) a fixed budget to
Was it possible to express indifference?	No
Were visual aids used?	Yes
Strength of preference examined at the individual respondent level?	No

Record	**Skedgel, C., Wailoo, A. and Akehurst, R., 2014. Societal preferences for distributive justice in the allocation of health care resources: a latent class discrete choice experiment. Medical Decision Making, 35, 94-105.**
Number of tasks completed by each respondent	11
Time taken to complete survey reported?	Yes – 9.5 minutes on average (public)
Summary of finding: end of life vs. non-end of life	Evidence not consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	Evidence of support for treating younger and larger patient groups; and for deprioritising treatment for those who will be in poor health after treatment
Other factors examined	Age, quality of life without treatment, quality of life with treatment, number of patients treated
Impact of background characteristics reported?	Yes – background characteristics were not statistically significantly associated with (latent) class membership
Were qualitative data or explanatory factors sought?	No / not reported
Was any reference made to age-related preferences?	Yes – evidence of support for treating younger patients, though the author did not interact the age and life expectancy without treatment variables
Was any reference made to time-related preferences?	No

Record	**Stahl, J.E., Tramontano, A.C., Swan, J.S. and Cohen, B.J., 2008. Balancing urgency, age and quality of life in organ allocation decisions—what would you do?: a survey. Journal of Medical Ethics, 34, 109-115.**
Year of publication	2008
Year of study conduct	Not reported
Country or countries of origin of data	USA
Sample size	623
Type of sample	Public
Sample recruitment process	Internet panel
Criteria for excluding respondents and/or observations reported?	No
Mode of administration	Internet survey
Summary of primary study objective(s)	To test for support for multiple prioritisation criteria
Was end of life (or a related term) mentioned explicitly in the study objectives?	Yes
Pilot reported?	No
Preference elicitation technique	Other choice exercise
Perspective	Social decision maker
End of life definition	Urgency (life expectancy without treatment)
Life expectancy without treatment attribute levels	Levels not reported explicitly, but appear to cover: <1mth, 3mths, 6mths, 9mths, 12mths, 15mths, 18mths, 21mths, 24mths
Life expectancy gain from treatment attribute levels	1yr, 2yrs, 3yrs, 4yrs, 5yrs, 6yrs, 7yrs, 8yrs, 9yrs, 10yrs
Was disease labelled or named?	Yes – organ transplantation
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No
What were respondents choosing between (or choosing to do)?	Which of two patients to give an organ transplant to
Was it possible to express indifference?	Yes – a 'can't decide' option was available
Were visual aids used?	No
Strength of preference examined at the individual respondent level?	Yes – attribute levels were varied incrementally

Record	**Stahl, J.E., Tramontano, A.C., Swan, J.S. and Cohen, B.J., 2008. Balancing urgency, age and quality of life in organ allocation decisions—what would you do?: a survey. Journal of Medical Ethics, 34, 109-115.**
Number of tasks completed by each respondent	33 (unclear whether each respondent answered all or a subset of the 33)
Time taken to complete survey reported?	No
Summary of finding: end of life vs. non-end of life	Evidence consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	When both patients have better (worse) than average quality of life, respondents preferred to treat the worse-off (better-off) patient
Other factors examined	Age, life expectancy with treatment, quality of life without treatment, quality of life with treatment; single-factor and cross-factor trade-offs examined
Impact of background characteristics reported?	Yes – older (>40yrs) and female respondents had narrower windows of indifference – i.e. preferred to treat end of life patient until the difference between the life expectancies of the patients was extremely small; respondents with transplant recipient in family placed greater importance on quality of life without treatment then life expectancy without treatment unless the latter was extremely short (<1mth)
Were qualitative data or explanatory factors sought?	No / not reported
Was any reference made to age-related preferences?	Yes – for an older patient to receive priority over a younger patient, the older patient must be at least 2.5mths closer to their end of life than the younger patient
Was any reference made to time-related preferences?	No

Record	**Stolk, E.A., Pickee, S.J., Ament, A.H. and Busschbach, J.J., 2005. Equity in health care prioritisation: an empirical inquiry into social value. Health Policy, 74(3), 343-355.**
Year of publication	2005
Year of study conduct	Not reported
Country or countries of origin of data	Netherlands
Sample size	65
Type of sample	Students, researchers, health policy makers
Sample recruitment process	Not reported
Criteria for excluding respondents and/or observations reported?	No
Mode of administration	Non-computer-assisted personal interview
Summary of primary study objective(s)	To test for support for multiple prioritisation criteria
Was end of life (or a related term) mentioned explicitly in the study objectives?	No
Pilot reported?	Yes
Preference elicitation technique	Other choice exercise
Perspective	Social decision maker
End of life definition	Information on life expectancy without treatment not provided explicitly but could be calculated given information on age, life expectancy (disease-free and with disease) and life years lost due to disease
Life expectancy without treatment attribute levels	0.5yrs, 2.25yrs, 3yrs, 11yrs, 14yrs, 14.5yrs, 16yrs, 20yrs, 20.5yrs, 22.5yrs
Life expectancy gain from treatment attribute levels	N/A – treated patient would be given a ‘wonder pill’ which would relieve them of all described health problems and bring them back to normal health
Was disease labelled or named?	Yes – each patient had a different disease
Did the study examine whether quality of life improving or life extending treatments are preferred for end of life patients?	No
What were respondents choosing between (or choosing to do)?	Which of two patients to treat
Was it possible to express indifference?	No
Were visual aids used?	No

Record	**Stolk, E.A., Pickee, S.J., Ament, A.H. and Busschbach, J.J., 2005. Equity in health care prioritisation: an empirical inquiry into social value. Health Policy, 74(3), 343-355.**
Strength of preference examined at the individual respondent level?	No
Number of tasks completed by each respondent	45
Time taken to complete survey reported?	Yes – 20 minutes on average
Summary of finding: end of life vs. non-end of life	Evidence not consistent with an end of life premium
Summary of finding: quality of life improvement vs. life extension	Not examined / reported
Other results of potential interest	Fair innings and (to a lesser extent) proportional shortfall approaches to priority-setting were highly correlated with the observed rank order implied by respondents' choices
Other factors examined	Fair innings, severity, proportional shortfall
Impact of background characteristics reported?	Yes – there were no major differences in the rank orderings of the three respondent subgroups
Were qualitative data or explanatory factors sought?	No / not reported
Was any reference made to age-related preferences?	Yes – treatments for elderly patients were not valued as higher prospective health theories that ignore the past (i.e. age) would have predicted
Was any reference made to time-related preferences?	No