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Valuing health at the end of life: A stated preference discrete choice experiment

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ABSTRACT

A source of debate in the field of health care priority setting is whether health gains should be weighted differently for different groups of patients. The debate has recently focused on the relative value of life extensions for patients with short life expectancy. However, few studies have examined empirically whether society is prepared to fund life-extending end-of-life treatments that would not meet the reimbursement criteria used for other treatments.

A web-based discrete choice experiment was conducted in 2012 using a sample of 3969 members of the general public in England and Wales. The study design was informed by the National Institute for Health and Care Excellence's supplementary policy for the appraisal of life-extending end-of-life treatments. The choice tasks involved asking respondents which of two hypothetical patients they would prefer to treat, assuming that the health service has enough funds to treat only one of them. Conditional logit regressions were used for modelling.

Choices about which patient to treat were influenced more by the sizes of treatment gains than by patients' life expectancy without treatment. Some respondents appear to support a health-maximisation type objective throughout, whilst a small minority always seek to treat those who are worse off without treatment. The majority of respondents, however, seem to advocate a mixture of the two approaches. Overall, we find little evidence that members of the general public prefer to give higher priority to life-extending end-of-life treatments than to other types of treatment. When asked to make decisions about the treatment of hypothetical patients with relatively short life expectancies, most people's choices are driven by the size of the health gains offered by treatment.

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1. Introduction

Economic evaluation is used to estimate the efficiency of health technologies and subsequently to inform decisions about whether those technologies should be reimbursed. A common approach is to measure the health benefits of a given technology in terms of quality-adjusted life years (QALYs) (Weinstein and Stason, 1977). The cost-effectiveness of the technology can be expressed as cost per QALY gained. Decisions about whether to reimburse the technology can then be guided by comparing the cost-effectiveness of that technology to some threshold value that reflects displaced activities (Towse et al., 2002).

If it is assumed that the principal objective of health care is to maximise population health using available resources (Culyer, 1997) and that the QALY is an acceptable measure of health benefit, it follows that health care resources should be prioritised so as to maximise the total number of QALYs gained. This 'QALY-maximisation' rule (Dolan et al., 2005) entails distributive neutrality – it does not incorporate concerns for how the benefits are distributed across individuals.

However, maximising health may not be the only purpose: health care systems may also have other objectives, such as reducing health inequalities. As well as evaluating the evidence on cost-effectiveness, agencies carrying out health technology appraisals are often expected to make and apply social value judgements, about what is appropriate and acceptable for society.

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Reviews by Schwappach (2002) and Dolan et al. (2005) show that people value QALYs differently depending on how they are distributed, the characteristics of the patients receiving them, and the characteristics of the health effects.

Health care decision makers in a number of countries have been considering whether and how to weight health gains to account for equity considerations, such as concern for those whose health prospects are poorest. In the Netherlands, for example, broad consensus has been reached to use the principle of 'proportional shortfall' as the basis for equity weighting (van der Wetering et al., 2013). This involves giving priority to patients who will lose the greatest proportion of their remaining health expectancy due to their condition. In England and Wales, the National Institute for Health and Care Excellence (NICE), the organisation responsible for producing advice on the use of health technologies in the National Health Service, has introduced a policy that effectively gives higher priority to life-extending, 'end-of-life' treatments than to other types of treatments. This constitutes a departure from the Institute's 'reference case' position (NICE, 2013) whereby all QALYs are deemed to be of equal social value, regardless of to whom they accrue and the context in which they are enjoyed. This paper examines society's preferences regarding the prioritisation of life-extending end-of-life treatments. The NICE policy is used as an example and as the framework for the study design. However, the issues explored have relevance in all countries seeking to understand the extent of societal support for giving priority to patients with short life expectancy.

1.1. NICE's end-of-life policy

In January 2009, NICE issued supplementary advice for appraising life-extending, end-of-life treatments (NICE, 2009a). This advice constitutes an explicit departure from the reference case position above. It indicates that if certain criteria are met, it may be appropriate to recommend the use of treatments for terminal illness that offer an extension to life even if their base case cost-effectiveness estimates exceed the range normally considered acceptable (Rawlins and Culyer, 2004).

The current criteria, enshrined in NICE's updated methods guide (NICE, 2013), are set out below; if met, the Appraisal Committee is asked to consider the impact of giving greater weight to the treatment gains achieved in the later stages of disease.

1. The treatment is indicated for patients with short life expectancy (normally less than 24 months).
2. The treatment offers an extension to life compared to current NHS treatment (normally at least three additional months).
3. The treatment is licensed, or otherwise indicated, for small patient populations (normally less than 7000 patients).

In response to concerns expressed during the consultation that there is little evidence to support the premise that society is prepared to fund life-extending end-of-life treatments that would not meet the cost-effectiveness criteria used for other treatments (NICE, 2009b), a few studies of people's preferences regarding end-of-life have been undertaken in the UK (Linley and Hughes, 2013; Brazier et al., 2013) and elsewhere (Olsen, 2013; Pinto-Prades et al., 2014). The findings are mixed, with evidence of support for an end-of-life premium reported by Brazier et al. (2013) and Pinto Prades et al. (2014) but not by Linley and Hughes (2013) or Olsen (2013). Notwithstanding these recent additions to the empirical literature, the evidence remains limited and there have been calls for further exploration of the issues (Green, 2011).

1.2. Objectives

The primary aim of this study is to investigate the extent to which the policy of giving higher priority to life-extending end-of-life treatments (as defined by NICE) than to other types of treatment is consistent with the stated preferences of members of the general public in England and Wales. Preliminary studies, reported elsewhere (Shah et al., 2011; 2014), tested the proposed methods and found weak evidence of public support for giving priority to end-of-life patients, all else being equal. A further aim is to add to the growing literature on public preferences regarding the prioritisation of health care, which can be used to support an 'empirical ethics' approach to allocating health care resources (Richardson and McKie, 2005).

2. Methods

2.1. Framework

There are many stated preference techniques that can be used to elicit public preferences regarding health care priority setting (Ryan et al., 2001). Health economists typically prefer choice-based techniques that reflect the view that the value of something is measured by how much one is willing to trade or sacrifice to obtain it. One such technique, the discrete choice experiment (DCE), produces quantitative trade-offs between different factors based on hypothetical choices (Louviere et al., 2000). DCEs are typically implemented in surveys comprising several 'choice sets', each containing competing alternative 'profiles' described using 'attributes' and a range of attribute 'levels'. Respondents are asked to choose between these alternative profiles, and the resulting choices are analysed to estimate the relative contribution of each of the attribute levels to overall utility (Lancsar and Louviere, 2008).

DCE data are modelled within a random utility framework, which assumes the utility (U_{nj}) that respondent n obtains from choosing alternative j can be separated into an explainable component (V_{nj}) and an unexplainable component (ε_{nj}):

$$U_{nj} = V_{nj} + \varepsilon_{nj}$$

The researcher does not observe ε_{nj} and treats it as random. Assuming that the random terms are independently and identically distributed extreme value, the conditional logit model can be used to estimate the probability of alternative i being chosen from the complete set of alternatives ($j = 1, \ldots, J$):

$$P_{ni} = \frac{e^{V_{ni}}}{\sum_{j=1}^{J} e^{V_{nj}}} \quad j = 1, \ldots, J$$

2.2. Attributes and levels

The selection of attributes and levels (Table 1) was based on NICE's criteria (above) and informed by the findings of our preliminary studies (Shah et al., 2011; 2014). 'Life expectancy without

Table 1
Attributes and levels used in the study.

Attribute	Unit	Levels
Life expectancy without treatment	Months	3, 12, 24, 36, 60
Quality-of-life without treatment	%	50, 100
Life expectancy gain from treatment	Months	0, 1, 2, 3, 6, 12
Quality-of-life gain from treatment	%	0, 25, 50

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