# **NIHR** Policy Research Unit in Adult Social Care



Funding and resource decision-making for adult social care – the role of costeffectiveness analysis

Julien Forder and Daniel Roland

December 2021



THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE





### DISCLAIMER

This report is based on independent research commissioned and funded by the National Institute for Health Research (NIHR) Policy Research Programme through its core support to the Adult Social Care Research Unit (PR-PRU-1217-21101). The views expressed are those of the authors and are not necessarily those of the NIHR or the Department of Health and Social Care.

# Contents

Summary1
Introduction1
Cost-effectiveness research in social care1
Applying a cost-effectiveness approach in social care1
Values and social care1
Methods for economic evaluation in social care2
Using cost-effectiveness evidence to inform social care resource decisions
Concluding comments
Introduction5
Cost-effectiveness research in social care5
Developing evidence base5
The use of cost-effectiveness research in practice6
Applying a cost-effectiveness approach in social care7
Values and social care7
Need adjustments - The Rule of Rescue and End-of-life premium
Methods for economic evaluation in social care9
Unit of analysis9
Outcome indicators for social care evaluation9
Attribution and comparators10
Perspective12
Engagement and supporting participation in research12
Using cost-effectiveness evidence to inform social care resource decisions
Discussion14
Development15
Principles15
Technical issues15
Using CEA to inform decision making in SC15
Implementation16
Concluding comments
Appendix17

# Summary

## Introduction

- Policy makers, operating with finite public budgets and facing increasing need, have choices in what care and support to fund. Cost-effectiveness analysis (CEA) is an approach that can help with these choices. This paper is concerned with the social care system in England, the system of long-term care and support for people with impairment, frailty and disability.
- 2. CEA is a tool to determine the optimal allocation of scarce resources which embodies certain principles, value judgements and assumptions (Levin and McEwan, 2001). This approach is used extensively in healthcare but less so in social care. The aim of this paper is to identify the issues and potential developments that would support further use of CEA in adult social care.
- 3. We focus on three areas. First, the need to establish whether the underpinning values of the care system justify a cost-effectiveness approach. These value judgements and concepts that underpin a CE approach have not been widely debated in the social care arena and are, arguably, not part of the routine discourse, nor practice in this field. Second, to consider how economic evaluation methodologies apply in social care (to be used to produce evidence for CEA). Third, with how CEA evaluation evidence can be used to inform decision-making, particularly the use of a cost-effectiveness threshold, and how a threshold might be determined for social care.

## Cost-effectiveness research in social care

- 4. The evidence base in social care appears underdeveloped. A systematic literature review carried by Weatherly et al. (2017) identified 30 economic evaluation studies in social care. Another systematic literature review, by Bulamu, Kaambwa and Ratcliffe (2018), focused on community care for older people and found only 11 articles after inclusion and exclusion criteria.
- 5. The degree to which CEA evidence is implemented in practice is hard to establish, although it appears modest. In England National Institute of Excellence in Health and Social Care (NICE), who have been responsible for issuing economic evaluation and guidance for healthcare since 1999, extended this remit to social care in 2013. NICE can highlight examples of the social care guidance it provides (NICE, 2019a), although these are a small proportion of the total including health-related guidance. There have been a range of recent initiatives to promote implementation in social care, recognising the challenge (e.g. the ESSENCE project <a href="https://essenceproject.uk/">https://essenceproject.uk/</a>).

# Applying a cost-effectiveness approach in social care

## Values and social care

- 6. A CEA approach embodies a *utilitarian* value principle i.e. that a gain in wellbeing is valued equally whoever benefits and regardless of how that benefit is achieved (Lowry and Peterson, 2011; Marseille and Kahn, 2019). Such an approach can be at odds with other principles, potentially those that involve achievement of basic human rights, those that seek to protect the most vulnerable/in-need, etc. There are ways to adapt a CEA approach to account for some of these concerns but these adjustments might be seen as somewhat arbitrary (Lowry and Peterson, 2011; Marseille and Kahn, 2019).
- 7. There are many core similarities between social care and health care where CEA/utilitarianism is widely used for the latter. As such it would be surprising if the case of social care was fundamentally at odds with this position, but we do reflect that some of these alternative value principles appear to be particularly relevant in social care which seeks to help people that are

often vulnerable, unsafe, and/or deprived. We argue that further exploration/debate should be had about these principles for social care.

### Methods for economic evaluation in social care

- 8. Most evaluation studies have the direct care recipient as the *unit of analysis*. Social care interventions often also affect the person's carers, particularly family members (Bressan, Visintini and Palese, 2020; Teno et al, 2004), and this impact should be taken into account, although it appears to be done rarely (Weatherly *et al.*, 2017). One approach is to combine outcomes measured separately, using relevant measures for carer impact e.g. ASCOT-Carer (Rand *et al.*, 2015; Batchelder *et al.*, 2019). Questions remain however about how they should be combined (e.g. by unweighted addition, or otherwise), also recognising the interdependency of outcomes for the cared-for person and their carers (Rand, Forder and Malley, 2017; Rand, Malley and Forder, 2019). An alternative approach is to develop outcome measures that work for the household. To date there appears to be very little research on the latter.
- 9. Generic, preference-weighted outcome indicators are a core component of CEA, measuring both mortality risk (life years lost) and quality-of-life outcomes. Two such measures used in social care evaluation have been recommended (Makai *et al.*, 2014): the Adult Social Care Outcome Toolkit (ASCOT) (Netten *et al.*, 2012) and the Index of Capability ICECAP (Coast *et al.*, 2008). Appropriate indicators focus on measuring improvements in wellbeing (not personal impairment), being sensitive to aspects of quality-of-life that social care can affect (Forder and Caiels, 2011). Social care mainly helps people function given their impairment; it is not aimed at helping to 'treat' that impairment.
- 10. These outcome measures are being increasingly used in social care evaluation studies, but their use in social care practice, e.g. person-level care planning, appears more limited. In some cases 'personal outcome' approaches are used in practice, where service users are asked to state outcomes they want to achieve, and this is monitored through time (Apps, Crowther and Forder, 2013). The limitation is that (by definition) there is no standardisation to allow comparison between different service users and services.
- 11. Self-reporting of health and wellbeing is not always suitable in social care, where people often suffer cognitive impairment. Rather, measurement has adapted to use proxies and/or (trained) observers to determine patients' well-being and quality of life (Arons *et al.*, 2013; Rand and Caiels, 2015; Rand *et al.*, 2017). ASCOT has both these options (Towers *et al.*, 2019).
- 12. Regarding the *effect* of a new intervention in comparison to an alternative i.e. comparing its outcomes with the 'counterfactual' case where that new intervention is not used an established method is the experimental study (especially randomised control trials/RCTs). This approach is rare in social care evaluation (Weatherly *et al.*, 2017), perhaps due to ethical concerns and also the 'complexity' (for research) of many social care interventions. The former might concern distrust of study designs that deny interventions to (control groups) of people that are expected to benefit from those interventions. The latter can mean that RCT results are either conditional on the circumstances of the study or are hard(er) to interpret (e.g. their effect is dependent on the person's circumstance, their condition etc.).
- 13. Non-experimental (observational) studies e.g. those that use data collected about people as they use (new) interventions in practice can also be used for evaluation. Ethical and complexity issues are less of an issue in this case. However, despite significant advances in relevant (statistical) methods, (attribution) bias in establishing causal effects (e.g. due to selection) cannot be ruled out in these designs. Studies combining experimental and observational elements can be a solution to these challenges.

14. The ethical concerns (with RCTs) stem, to some extent, from the values and principles that underpin the provision of care. In the utilitarian/CEA discourse, the idea of the opportunity cost of decisions is central. RCTs can then be justified on the basis of *equipoise* – genuine uncertainty about which intervention is 'best'. This argument is more challenging when human rights and equality are seen as guiding principles (although still relevant where there are different competing options to achieve these aims).

#### Using cost-effectiveness evidence to inform social care resource decisions

- 15. To achieve greatest benefit (wellbeing) with a CEA approach for decision-making, the most costeffective option is identified for funding first, followed successively by the next best costeffective options and so forth until the budget is exhausted. Any new *and* more cost-effective intervention would be funded, displacing the least cost-effective prevailing option. Rather than identify the actual cost-effectiveness level of the latter, a 'cost-effective threshold' is often used in practice to provide this benchmark.
- 16. Currently, we lack an agreed CE threshold for social care. The threshold for the health system used by NICE is £20,000-£30,000 per QALY, and this level is well-established. Other studies have estimated, nonetheless, that the opportunity cost of health care in England (the marginal cost-effectiveness of health care) has a lower value, of around £13,000 per QALY (Claxton *et al.*, 2015).
- 17. There is some research on the marginal cost-effectiveness of social care. One study of community-based social care suggests an incremental cost-effectiveness ratio (ICER) using ASCOT that is the cost of producing an extra year in good wellbeing for a social care recipient is around £15,000 or more if additional funding is used to increase the number of service users who are eligible for (i.e. have *access* to) support in the care system (Forder *et al.*, 2018). However, for marginal increases in the *intensity* of care for existing service users (e.g. additional hours of care per week for existing service users), ICERs were higher, at £65,000 for high-need groups and £45,000 for low-need groups.
- 18. Another study (Longo *et al.*, 2021), considered the marginal effect of LA-average social care expenditure per capita (of all types) and found an incremental cost per social care-quality-adjusted life year (using ASCOT) of £333,333 per year. Compared to the estimates in Forder *et al.* (2018) for increasing intensity this is a somewhat higher figure. There are some key differences in these studies, including their focus and approach, the latter reflecting the challenges in establishing the 'counterfactual' effect difference.
- 19. In applying CEA in social care, another issue is about how to account for the health-related impacts of social care decisions (noting that health care and social care are different system in England). The standard calculus of comparing the cost-effectiveness (i.e. ICER) of a new social care intervention to a social care CE threshold (were one to be established) will not produce optimal decisions about the use of social care if there are interdependencies between these sectors, as appears to be the case (Forder, 2009; Forder, Gousia and Saloniki, 2019). In this case further adjustment is needed to account for the knock-on (spill-over) effects e.g. that more social care produces better outcomes for service users and also benefits in the health system. Similar adjustment is needed when factoring-in informal care. Such comparisons require either universal outcome indicators or established 'exchange rates', to read between social care and health outcome indicators (like ASCOT and EQ-5D). Early studies regarding the latter do suggest that exchange rates may be close to one-for-one.

# Concluding comments

- 20. We are seeing the evidence base develop, with a range of initiatives and research funding calls, but there are some questions about the application of CEA in social care. These concern: (a) the values and principles that underpin what the (public) care sector is trying to achieve, and in turn what the desired outcomes are for (CEA) evaluations; (b) how decisions are made in social care using CEA evidence; and (c) how the sector can be best supported to implement evidence-based change in practice.
- 21. We propose that a debate involving sector bodies, representative organisations, the public and the academic community could help with these issues (especially the first concern), supplemented with research on current opportunity cost levels in social care.
- 22. We have proposed some approaches regarding the second concern, particularly research and consultation to establish a social care cost-effectiveness threshold. On the last, applied implementation research and support initiatives are being developed to help to get evidence into social care practice (e.g. the NIHR-funded ESSENCE project, and the ESRC/Health Foundation-funded IMPACT programme, as noted above).
- 23. Addressing these issues, we argue that CEA can play a greater role and produce significant benefit in the social care sector.

## Introduction

Policy makers, operating with finite public budgets and facing increasing need, have choices in what care and support to fund. Cost-effectiveness analysis (CEA) is one approach that can help decision makers. This paper is concerned with decisions in the social care in England, the system of long-term care and support for people with impairment, frailty and disability. CEA is a tool to determine the optimal allocation of scarce resources (in choosing public policies and making care choices) which embodies certain principles, value judgements and assumptions (Levin and McEwan, 2001). This approach is used extensively in healthcare (Detsky and Naglie, 1990; McCabe, Claxton and Culyer, 2012; Smith *et al.*, 2013) and there is a well-developed evidence base in health care of the (comparative) cost-effectiveness of a wide range of health care interventions and policies.

Health and social care share many goals and characteristics and decision makers face similar – and often interdependent – choices (Higgins, Oldman and Hunter, 1994; Shaw, Rosen and Rumbold, 2011). However, we argue that a cost-effectiveness approach is not as well developed in its use to support decision-making in social care. There are two broad aspects to this argument. First, the value judgements and concepts that underpin a CE approach have not been widely debated in the social care arena, and are, arguably, not part of the routine discourse, nor practice in this field. Second, there are a number of potential technical and implementation challenges in using a CE approach in social care – and these should be explored. These points relate to both the methods to develop CE evidence (to do the evaluations and the research) and also in the way that CE evidence is used to inform social care decisions. Reflecting the significance of these two issues, we observe that the social care CE evidence base is less developed than that in health care.

There is, nonetheless, recognition of the importance of developing this evidence base and using it to inform policy and practice decision-making. England's National Institute of Excellence in Health and Social Care (NICE), responsible for issuing economic evaluation and guidance for healthcare since 1999, has started doing similar work on social care since 2013. There are also initiatives to develop the evidence – for example, the ESSENCE (Economics of Social care compendium) project.<sup>1</sup>

The aim of this paper is to identify the issues and potential developments that would support a more extensive and routinised use of CEA in adult social care. We begin with an overview of the availability of CEA evidence in social care and consider the use of CEA research in care practice. We then consider the gaps in current knowledge about the application of CEA in social care and suggest some solutions and ways forward. In doing so, we distinguish between three issues. First, relating to the underpinning values of the care system, which might or might not justify a cost-effectiveness approach. Second, concerning the main methodological challenges in using CEA to develop the evaluation evidence. Third, with how CEA evaluation evidence can be used to inform decision-making, particularly the use of a cost-effectiveness threshold, and how this might be determined for social care (given that a well-defined threshold is not currently available for social care). We conclude with some recommendations about policies that might support these developments of the CEA agenda.

# Cost-effectiveness research in social care

## Developing evidence base

A systematic literature review carried by Weatherly et al. (2017) identified 30 economic evaluation studies in social care. The review's purpose was to inform strategy for including (social care)

<sup>&</sup>lt;sup>1</sup> https://essenceproject.uk/

economics in social care guideline development, given the heterogeneity of methodological approaches. A little less than half the studies identified in the review used a randomised controlled trial setup. The remaining articles used a number of approaches, including large-scale observational data analysis, with methods such as propensity score matching and difference-in-difference analysis. As observed by the authors, economic evaluations in social care differed in most aspects listed in the analysis by the review – (i) perspective, (ii) comparators, (ii) evidence, (iv) opportunity costs, (v) uncertainty and (vi) equity – with some aspects absent altogether from some studies. Some studies did refer to method guidelines from NICE and other known sources, but they lacked standardisation and some aspects of this were absence, suggested the need for further development work. For example, although studies were noted to be of good quality and based on robust study designs, there was no consistency in the approaches undertaken to examine cost-effectiveness – often reflecting the lack of an agreed cost-effectiveness threshold in social care. In the main, the comparison in the studies was limited to two options only, the intervention and an alternative.

Another systematic literature review, by Bulamu, Kaambwa and Ratcliffe (2018), focused on community care for older people and found only 11 articles after inclusion and exclusion criteria. Nearly three quarters of the studies were conducted in Europe. All of these studies used health-related quality of life measures (mainly EQ-5D-3L) for cost-effectiveness, cost-utility or cost-consequence analysis. Only two highlighted the relevance of care-related quality of life measures (such as the Adult Social Care Outcomes Toolkit and the ICECAP-O capability measure).

#### The use of cost-effectiveness research in practice

Investment in developing the CE evidence base will only have impact if that research is implemented appropriately in everyday decision making about social care. CE evidence can inform decisions about funding, commissioning and delivery of care. Relevant research can be used by Government in spending reviews to help determine levels of public funding for social care. Most often this evidence is used to develop practice guidance. NICE disseminates social care guidance, collaborating with Skills for Care, the Local Government Association, the Association of Directors of Adult Social Services and others; they are able to give a range of examples of how their guidance is being used (NICE, 2019a). Another initiative, the ESSENCE project, funded by the National Institute of Health Research (NIHR) provides a case studies and research summaries on cost-effectiveness on social care, aiming to improve access to the most recent research and findings in social care (Care Policy and Evaluation Centre, no date). A new initiative, Improving Adult Care Together (IMPACT) funded by the Economic and Social Research Council (ESRC) and the Health Foundation aims to support the implementation of 'evidence of what works' in social care.

These initiatives seek to translate research finding into recommendations and guidance for practitioners. However, even where practical guidance is available, it does not necessarily mean that practice and service changes happens. The care regulator, the Care Quality Commission (CQC) has contributed to evidence-based service adoption. When assessing services within the "effective" domain (one of five domains which form the key lines of enquiry) providers are rated on whether "treatment and support achieves good outcomes, promotes a good quality of life and is based on the best available evidence" and in particular is in line with "evidence-based guidance" (Care Quality Commission, 2017)

The role of workers and their interest in evidence-based practice is also important. A local study in the north of UK with 595 social care practitioners indicated that just over 50% of respondents favoured evidence-based practice within social care (Booth, Booth and Falzon, 2003). There are barriers to implementation (of evidence-based social care practices), including lack of accessibility to

relevant information and not enough time to find and read relevant guidance. Further research in Australia supported the hypothesis that training and experience were important in the process of acquiring research skills, facilitating access to research guiding evidence-based practices as suggested by a higher prevalence of use of research by managers and senior social care workers (Gray *et al.*, 2014)

Other social care stakeholders have identified access to research as an issue. For example, the Association of Directors of Adults Social Services (ADASS), in a report submitted to the UK's Members of Parliament regarding an inquiry on dementia care and services, noted 'the lack of clarity about what prevention and early intervention services are most effective' act as barriers to saving money whilst ensuring good quality of life for dementia patients (Association of Directors of Adult Social Services, 2011).

# Applying a cost-effectiveness approach in social care

## Values and social care

There are on-going debates about the ethical principles which should apply in decision making, and whether the application of CEA is consistent or compatible with these. In general (although not unanimously) CEA is associated with the principle of *utilitarianism*, essentially that it supports the social objective of maximising wellbeing, happiness or utility, irrespective (intrinsically) of who benefits (Lowry and Peterson, 2011; Marseille and Kahn, 2019). A number of alternative criteria and associated ethical principles, seen as (to varying degrees) incompatible with utilitarianism, include: those focusing on reducing inequity; those responding to need (especially where identified lives are in urgent need and/or imminent danger); and those based on a human rights principle.

It is not our intention to rehearse the arguments in this paper except to assert that some of these alternatives appear (more) relevant in social care – which seeks to help people that are often vulnerable, unsafe, and/or deprived. Principles of human rights – which are at the centre of social work practice (Harms-Smith *et al.*, 2019) – and an explicit consideration of equality seem especially relevant. Our main point, nonetheless, is that to our knowledge these debates have not been significantly aired in social care, and that it is self-evident that they should be, at least in considering a framework for allocating scarce care resources.

There are many core similarities between social care and health care, and we see widespread adoption of CEA and its underpinning utilitarian principle in the latter, not least as prominently underlined by the role of NICE in guiding health care decisions. As such it would be surprising if the case of social care was fundamentally at odds with this position regarding health care. Rather we expect there to be differences in emphasis. And in this regard, it is worth observing that principles such as human rights and equality need not be incompatible with a CEA approach.

As argued by Lowry and Peterson (2011) it might be possible to identify a space or set of decisions about care, and care resourcing, which are filtered out in accordance with associated human rights whilst the mainstream of care resources might be prioritised on a CEA (utilitarian) basis. Others argue that the perceived lack of intrinsic attention to equality issues with CEA may not in practice be so significant (Marseille and Kahn, 2019). Marseille and Kahn argue that there is less to object to because efficiency and inequality alleviation are often concordant. For example, the marginal effectiveness of additional care and support is greater for people with high needs than those with lower needs (e.g. see Forder *et al.*, 2018).

Regarding equality issues, an important question is whether the perception (and measurement) of value and quality of life should be adjusted for age and health characteristics. In health care, research on the variation of the value of statistical life (VSL) according to age is largely inconclusive – some finding little to no variation (Alberini *et al.*, 2004), some others finding an indication of a U-shaped relationship, with middle aged individuals valuing life the least while younger and older adults value life the most (Aidy and Viscusi, 2008).

#### Need adjustments - The Rule of Rescue and End-of-life premium

There have been considerations about more explicit adjustments in decision criteria in the health care space relating to need, and these appear especially relevant in social care. The Rule of Rescue, coined in 1986, provides an ethical discussion of the use of scarce resources to extend life in healthcare settings (Jonsen, 1986). The reasoning is that humans, in general, sense a moral obligation to spare no efforts in order to save a life, even if the resources could be used elsewhere to produce greater net benefits. A strictly utilitarian approach would not adequately reflect human nature in exceptional circumstances.

NICE does not explicitly considers the use of the Rule of Rescue in its core principles (NICE, 2021), having explored this issue previously in Citizens Council meetings. Nonetheless, the conclusion of their exploratory work did guide their implementation of end-of-life premiums for cost-effectiveness analysis, as outlined below, but not without some criticism on the suitability of such premiums and the validity of the questions listed (Cookson, McCabe and Tsuchiya, 2008). Furthermore, evidence presented by Charlton (2021) suggests that NICE's evaluation of drugs for treatment of conditions with a prevalence in individuals lower than one in fifty thousand, so called orphan-drugs, does seem to be based on the rule of rescue as the prioritisations of these drugs are not explained by the full articulation of any alternative set of rationales.

The evidence that age plays a role in the rationale for the Rule of Rescue is mixed. One study found that the imperative to save a human life over maximising wellbeing gains per money spent is reduced or absent altogether when the person whose life is to be saved is of 'old age' (Brazier *et al.*, 2014; Watters, 2015). However, another study showed that there is no effect of age in the analysis of the willingness to save a life in immediate peril (Shah, Tsuchiya and Wailoo, 2014).

Until recently, NICE used an end-of-life premium on their cost-effectiveness analysis of novel drugs and technologies that improved patients' Quality-Adjusted Life Year (QALYs). On top of the standard threshold of approval of £20,000-£30,000 per unit QALY gain, NICE would increase this up to £50,000 when analysing new life-saving drugs for the treatment of cancer (Paulden, 2017). This premium is being reviewed at the time of writing and might be replaced by another modifier based on severity of the disease and the associated treatment/technology being discussed (NICE, 2020).

The initial discussion of the Rule of Rescue precedes NICE's coverage of social care issues, which started in 2013. Many high-need users of social care would be at risk of death in being themselves unable (without support) to achieve fundamental activities of daily living (such as feeding), making a case for the Rule of Rescue (Forder and Fernandez, 2015). The apparent (implicit) weight of these arguments can arguably be seen in practice. The average annual cost of a nursing home in the UK stands over £47,320 a year (Laing, 2019) and even if we discount for the hotel costs, i.e. boarding, meals, laundry and utilities, it shows a willingness to pay a significant amount of money to meet the needs of older people, every year.

A further relevant consideration is to recognise the (positive) externalities that come from care and support. Like many aspects of social welfare, there are societal gains in the mere fact of knowing

that older people, one the most vulnerable elements of society, are being taken care of, even if at only basic levels of need. This rationale offers additional wellbeing derived from expenditure in social care but, understandably, it is not easily measured (Forder and Fernandez, 2015). It is an argument used to underpin the development of social insurance systems for LTC in other countries (Roland, Forder and Jones, 2021).

#### Methods for economic evaluation in social care

Accepting that a CEA approach should be considered in social care, in principle, a further set of issues concern the practical, technical and implementation challenges in using CEA in this field when developing (economic) evaluation evidence.

#### Unit of analysis

Most evaluation studies have the direct care recipient as the unit of analysis, measuring the benefits and costs of the intervention as they affect that individual. Social care interventions often affect not only the service user but also connected carers, particularly family members. People can be personally involved in providing care and can feel directly or indirectly responsible for the preservation of dignity and respect of their (cared-for) family member (Teno *et al.*, 2004; Bressan, Visintini and Palese, 2020). A cost-effectiveness analysis focused solely on the individual receiving social care, neglecting the impact on the carer's well-being, would underestimate the benefits of an intervention that could potentially be cost-effective when considering all parties involved.

One approach is to measure impacts on all people affected. This approach is endorsed by NICE, who determined in their guideline for care for people with Alzheimer's disease that the quality of life of carers should be included alongside quality of life of patients (NICE, 2011), a recommendation now made for all support for dementia or any long-term condition in general. Adoption of this approach appears somewhat limited. Weatherly et al., (2017) found that around 10% of economic evaluation studies in social care they reviewed measured outcomes for both the informal carer and the care recipient.

Relevant outcome measures for carers, such as ASCOT-Carer (Rand *et al.*, 2015; Batchelder *et al.*, 2019) have been developed and can combined with measures for cared-for people (e.g. ASCOT). Questions remain however, about how to combine outcomes as between the cared-for person and carer when assessing aggregate benefits and costs. For example, should they be added together (in some weighted combination)? To complicate this issue, research which suggests that the outcomes of care recipients (the cared-for person) are interdependently affected by their relationship with family members/carers (Rand, Forder and Malley, 2017; Rand, Malley and Forder, 2019).

An alternative approach is for studies to use the *household* as the unit of analysis, and to develop outcome measures that work for the household. To date there appears to be very little research on this question.

#### Outcome indicators for social care evaluation

Generic, preference-weighted outcome measures are a core component of CEA, reflecting both mortality risk (life years lost) and quality-of-life outcomes. Preference studies are used to establish the quality weight given to different health or wellbeing states, and to adjust (or 'anchor') the relative weights to allow trade-offs between mortality (risk) and quality of life (where have zero quality of life is regarded as indifferent from being dead). The EuroQol 5 Dimensions (EQ-5D) indicator is encouraged by NICE as a way to measure changes in health-related quality of life in adults which are then expressed in quality-adjusted life years (QALYs) (NICE, 2013, 2019b).

An emphasis on (improved) quality of life is particularly relevant in social care where the aim is to support people to best live with impairment and disability. In doing so, care services might also produce mortality reduction benefits. The challenge is finding a measure that is sufficiently comprehensive to address the range of quality-of-life improvements that social care can potentially affect, and allowing for these to be compared systematically, whilst being sensitive enough to measure meaningful change (Forder and Caiels, 2011).

Two measures used in social care evaluation that are designed in this way (Makai *et al.*, 2014), using preference weighting (and anchoring to death states) are the Adult Social Care Outcome Toolkit (ASCOT) (Netten *et al.*, 2012) and the Index of Capability - ICECAP (Coast *et al.*, 2008). They focus on measuring improvements in wellbeing (and not personal impairment). It is important that social care related quality of life measures are concerned with the outcomes that social care is designed to achieve. In particular, social care services such as home care and care homes help people function given their needs/impairment; they are not aimed at helping to 'treat' that underlying impairment (Forder and Caiels, 2011).

ASCOT covers eight domains of people's lives that might be affected by social care. Like the EQ5D QALY, ASCOT has preference weights which are anchored between a state equivalent to (i.e. as bad as) death and aspired (full) care-related quality of life (wellbeing). Stevens, Brazier and Rowen (2018) have estimated an exchange rate between ASCOT and EQ-5D-3L, using preference-based mapping via common time trade-off (TTO) valuations. Their findings indicated that ASCOT and EQ-5D-3L have an equivalence of almost one to one.

ICECAP uses five domains of wellbeing. It was refined into instruments such as the capability-based measure of general quality of life of older people - ICECAP-O (Flynn *et al.*, 2011). A comparability study with ICECAP-O, ASCOT and EQ-5D-3L showed that while the latter indicator captured physical health more accurately than ICECAP-O and ASCOT, mental health was better assessed by ICECAP-O and self-perceived quality of life was most strongly associated with ASCOT (Van Leeuwen *et al.*, 2015). The authors argued that ICECAP-O and ASCOT have a broader aim than EQ-5D for long-term care, and are deemed as suitable instruments to be used in social care economic evaluations.

Although measures such as ASCOT and ICECAP are being increasingly used in social care evaluation studies, their use social care practice, e.g. person-level care planning, appears more limited. Rather, 'personal outcome' approaches might be used in practice (Apps, Crowther and Forder, 2013), where service users are asked to state outcomes they want to achieve, and this is monitored through time. The limitation is that (by definition) there is no standardisation to allow comparison between service users and services.

A significant issue in social care concerns the high prevalence of cognitive impairment in cared-for populations. Self-reporting of health and wellbeing, a main method for measuring QALYs is not always suitable. One strategy is the use proxies or (trained) observers to determine service users' well-being and quality of life (Arons *et al.*, 2013; Rand and Caiels, 2015; Rand *et al.*, 2017). ASCOT has options for proxy reporting (e.g. by carers) and also for observational approaches (Towers *et al.*, 2019). Another strategy is to use advanced care planning, also known as end-of-life discussions, to determine patients' preferences before they reach the point where they are unable to convey them (Wright *et al.*, 2008; Detering *et al.*, 2010).

#### Attribution and comparators

There are a range of methods for evaluation studies to establish the counterfactual experience when considering social care interventions and policies, including controlled experimental and quasi-

experimental designs (with or without randomly allocated control groups) and non-experimental (observational) designs (Gillies *et al.*, 2016).

Whilst the former designs (especially randomised controlled trials/experiments) are regarded as having the greatest validity in establishing the causal effect of a new intervention (internal validity), their use in social care evaluations has been relatively limited (Weatherly et al, 2017). Two particular issues are (i) the ethical basis of experiments in social care, and (ii) the often-significant complexity of the 'intervention'. Ethical issues can be seen to arise out of potential denial/delayed use of services for control groups when professional judgement suggests that the new/to-be-tested intervention will be effective.

Interventions can be *complex* when the mechanisms of effect/process of the intervention (and so the outcome) is conditional on a whole range of factors, including the context in which the intervention is delivered, or when there are multiple components/inputs that work in combination (and interact in multiplicative ways) (Bonell *et al.*, 2012). These characteristics are challenging for any evaluation, but a particular charge against experimental designs is that they (by construction) seek to abstract out complexity, making it difficult to infer what the causal effect was, that is, how the change mechanism worked. A particular concern is that a (complex) intervention that is shown to be effective in an experimental context may not be so in everyday practice (with varying contexts etc.). The perceived value of doing RCTs (against their significant cost) may be relatively low in this case. There are also other issues, such as the inability to 'blind' the trial as between the intervention and control, and issues of 'contamination' of the control group intervention.

Non-experimental approaches can address some of these *external* validity issues, being based on everyday practice. However, there are also (potentially significant) limitations: primarily, attribution bias (e.g. due to selection) cannot be ruled out in these designs (although methods have developed to try to reduce this risk). Moreover, although the methods to reduce attribution bias often include controlling for context and complexity with data that measures these potential confounders, this approach relies on these data being available (in the right form). For example, administrative data rarely includes markers of all theorised factors (and often less-than-ideal outcome measures). Other methods, such as difference-in-difference, aim to cancel-out of baseline differences between recipients and non-recipients of the tested intervention, but can also limit the exploration of contextual effects.

A potential solution to these issues is to combine approaches, that is, design and use factorial experiments that compare (multiple) key components of an intervention, and where data on contextual factors is collected and analysed using observational methods (Gillies *et al.*, 2016). Mixed methods studies are also proposed in the analysis of complex interventions. We recommend further methodological studies in social care to help establish the types of evaluation which will be valuable (and credible) in social care.

A further consideration is the choice of comparators. As is well-established, when testing a new intervention – to assess whether it is cost-effective relative to a CE threshold – we ought to be comparing it with the next available (more) cost-effective alternative for the condition/group (Johannesson and Weinstein, 1993; Laska *et al.*, 1999). This requirement applies in two ways.

First, we should not compare with alternatives that are less (or not at all) cost-effective than other existing options for that condition<sup>2</sup>. Second, we should compare with an alternative for the condition that is the *next* better feasible option (i.e. the next more cost-effective option - specifically the

<sup>&</sup>lt;sup>2</sup> So called *dominated* alternatives.

option with a lower incremental cost-effectiveness ratio (ICER)). We would start by comparing the new intervention with the least cost-effective of the currently funded (i.e. sufficiently cost-effective) option. If the new intervention was strictly better (i.e. more cost-effective) then that current intervention would be displaced and we would move on to comparing the next lowest CE alternative, and so on. For example, suppose we are evaluating intensive home care (e.g. 14+ hours per week of care). Compared with no home care, this option might look cost-effective. However, intensive home care ought to be compared with standard home care (e.g. 7 hours per week) if that option is more cost-effective when *compared to no home care* than intensive home care when compared to no home care (i.e. where standard home care has a lower ICER compared to no home care than the equivalent ICER for intensive home care).

In practice it might be difficult to identify the appropriate comparator (often evaluations compare to 'usual' care without knowing whether the usual care is itself cost-effective compared to existing alternatives for the condition, including not providing usual care).

#### Perspective

Cost-effective analysis is used to inform public spending, and generally incorporates the perspective of a health and/or social care 'decision-maker' allocating a public budget (see below). External costs and benefits can also be incorporated to take a wider societal perspective (although with challenges for the complexity and reach of underpinning studies).

The social care system involves a substantial proportion of private (self-funded) transactions, and although these choices are for individuals and families, the public system has a statutory responsibility to provide information and advice and to manage local markets. Indeed, poor information can hinder private decision-making (and limit the functioning of markets). Provision/regulation of information about the cost-effectiveness of care options should help improve private decision-making.

#### Engagement and supporting participation in research

Engagement of care providers to take part in research can be difficult and encouragement is necessary (Smith *et al.*, 2019). With much of the delivery of care from providers in the private sector, the goals of these organisations need not fully align with (public good) research. Mechanisms to reward/reimburse organisations for research-related costs are a practical requirement.

## Using cost-effectiveness evidence to inform social care resource decisions

CEA provides criteria for decision-makers in aiming to maximise the objective of the care system (as measured) from a given budget. In social care in England, this objective is generally understood to be the *wellbeing* of people with care needs, as set out in the 2014 Care Act, and the outcome measures outlined above (e.g. ASCOT) can be taken as measures of wellbeing. The decision to fund a social care intervention is made by comparing the benefits it is expected to create (improvements in wellbeing) against the opportunity cost of that choice, where the latter is the improvement in wellbeing that is forgone by displacing another (existing) social care intervention. Conventionally, this decision criteria involves comparing the incremental cost-effectiveness of the new intervention against a cost-effectiveness threshold that represents the opportunity cost of the displaced intervention (noting the above issues about appropriate comparators).

The threshold should represent the least cost-effective alternative care intervention currently being used within the current given budget (and so the first to be displaced) (Claxton *et al.*, 2011; Van Baal, Meltzer and Brouwer, 2016). Alternatively, the threshold can be seen to represent the (greatest) willingness to pay for interventions to improve wellbeing (where the budget is not fixed).

The NICE health threshold is £20,000-£30,000 per QALY, although estimates of the marginal costeffectiveness in the UK health system give a lower value, of around £13,000 per QALY (Claxton et al., 2015). A recent review of seventeen countries concluded that most national cost-effectiveness thresholds identified fall within the WHO's recommended range of one-to-three times GDP per capita, although also noting issues with the quality and quantity of data available in doing so (Cameron, Ubels and Norström, 2018). A willingness to pay threshold is used by the Government with each QALY gained worth £60,000 (HM Treasury, 2018). There are plans to review and possibly update this guidance, although an initial study described the difficulties in calculating the willingness to pay for QALYS and in fact only found three studies that undertook such task in the UK (Chilton et al., 2020). Three particular difficulties can be identified. First, the consideration of discounting, where evaluation takes into account the value of health in time. Second, the health baseline, where the state in which the individuals evaluated present themselves is measured as it could yield different measures of QALY gain given a treatment. And third, the scope insensitivity, a problem that frequently presents itself in willingness to pay studies as individuals do not show different reactions to different scenarios. For example, Beattie et al. (1998) reported that 42% of respondents gave the same answer for two different scenarios.

An important proposal by Chilton et al. (2020) is that different health measures, namely the Value of Life Year (VOLY), the Value of Prevented Fatality (VPF) and the QALY can all be derived empirically from a common source, reflecting the same underlying preferences over health and safety, maximising consistency across policy appraisals in health and social care.

A cost-effectiveness threshold has not yet been determined for social care in England. It appears reasonable to make reference to the cost-effectiveness threshold for health care used by NICE in the UK, particularly because research comparing the value of the a EQ5D QALY and an ASCOT care QALY suggests that they are very similarly valued (Stevens, Brazier and Rowen, 2018). However, this equality of thresholds argument only holds, strictly speaking, when health and social care are funded from the same budget, when in practice they are not (or at least not directly).

There is some research on the marginal cost-effectiveness of social care. One study of communitybased social care suggests an incremental cost-effectiveness ratio (using ASCOT) of around £15,000 or more for marginal increases in the number of service users in the care system (i.e. access to the care system) (Forder *et al.*, 2018). However, for marginal increases in intensity (e.g. additional hours of care per week for existing service users), ICERs were higher, at £65,000 for high-need groups and £45,000 for low-need groups.

Another study (Longo *et al.*, 2021), considered the marginal effect of LA-average social care expenditure per capita and found an incremental cost per social care-quality-adjusted life year (using ASCOT) of £333,333 per year. This is the marginal effect of an additional pound spent on the current population of care users. Compared to the estimates in Forder *et al.* (2018) – for increasing intensity – this is a somewhat higher figure. There are some key differences in these analysis. First, Longo *et al.* analysed the effects of LA-level adult social care expenditure per capita – on short- and long-term support, including for care homes – on outcomes of clients in the Adult Social Care Survey (ASCS), whereas Forder *et al.* used cost-weighted utilisation of community-based care (not care homes) at individual client level (with directly linked outcomes for the client). Measuring outcomes for people in care homes is particularly challenging given the high levels of cognitive impairment, and the ASCS under-represents residents (due to mental capacity). Second Longo *et al.* do not control for activities of daily living (ADL) need at individual person level. A key measure of need, used to determine eligibility and level of care in the care system, is the number and type of ADLs (e.g. dressing, feeding) that the individual cannot achieve themselves (without care support). ADLs are social care needs

(personal functioning), not outcomes – social care supports people to live with these impairments e.g. care workers help people to dress and feed when (because) they cannot achieve this themselves. As noted above, this is distinctive from a health care philosophy which is focused on improvements in personal functioning (e.g. self-care) as an outcome. Expenditure per service user is positively correlated with ADL need.

These results give some early indication of the opportunity cost of social care expenditure, which could be used to determine a CE threshold. However, with the range of estimates available, and the different interpretation of the marginal change (access or intensity), more work is needed to inform of the setting of a CE threshold in social care.

Another issue concerns the (current) separation of decision making and budgets between health and social care. The standard calculus of comparing the incremental cost-effectiveness ratio (ICER) of a new social care intervention with a social care CE threshold (were one to be established), will not produce optimal decisions about the use of social care where there are interdependencies between these sectors, as appears to be the case (Forder, 2009; Forder, Gousia and Saloniki, 2019).

Furthermore, current practice appears to treat the CE threshold as fixed – and therefore more aligned with the notion of it being a willingness to pay threshold. However, for a CEA approach to produce optimal decisions with fixed budgets, any new intervention adopted should lead to a change (reduction) of the CE threshold.

We illustrate these issues more formally in the appendix.

## Discussion

The application of CEA can lead to services and support being deployed in a way that maximises the gains in well-being of people with care needs when operating from a given budget. This outcome aligns with 2014 Care Act goal of maximising wellbeing. As shown in Forder and Fernandez (2015) a CEA approach will produce a different deployment of social care interventions than one based on a needs-first rule (which is perhaps a closer approximation of current practice), with a CEA-based deployment giving higher total wellbeing. With annual public spending on adult social care running to £20bn or more, even small improvements in cost-effectiveness can lead to substantial pound-savings or pound-value returns.

There are, nonetheless, a range of conditions for a CEA approach to deliver this wellbeing improvement focused outcome. A first, obvious requirement is to have a well-developed evidence base – to give estimates of (incremental) cost-effectiveness of interventions. Reviews to date point to further opportunities to develop CE evidence in social care. In England, there has been significant increased attention (and funding) to help address this shortfall, including through public programmes, particularly through NIHR, such as the School for Social Care Research, the Policy Research Unit programme, and the Applied Research Collaborations (ARCs).

Two further requirements, that we discuss more fully below are: (a) that the developed evidencebase (concerning the range of potential social care interventions) is interpreted and used appropriately to inform decision-marking; and (b) that the implications of a CEA approach are implemented to guide the decisions of social care providers and commissioners in practice.

## Development

#### Principles

A CEA approach is underpinned by a utilitarian value principle i.e. that a gain in wellbeing is valued equally whoever benefits and however it is achieved. Such an approach can be at odds with other principles, particularly those that involve achievement of basic human rights, those that seek to protect the most vulnerable/in-need, etc. There are ways to adapt a CEA approach to account for some of these concerns but these adjustments might be seen as somewhat arbitrary. We argue that a debate about these principles should be had for social care.

### Technical issues

Developments in outcome measurement for social care – e.g. to capture utility-weighted social care related quality of life – have allowed a more relevant set of potential impacts of care to be incorporated in CEA. We argue that further consideration is required about the unit of analysis, particularly the option to measure impacts on the household (cared for person and carers).

There are relatively few controlled (esp. RCT) studies in social care, which might in part be due to methodological issues – e.g. many social care interventions are 'complex' – or ethical concerns, particularly a distrust of designs that deny interventions to (control groups) of people that are expected to benefit from those interventions. Compared to health, there have been fewer opportunities for funding for evaluation studies.

As to the former, we argued above that the development of hybrid and mixed methods designs can help to mitigate this issue. Ethical concerns stem, to some extent, from the values and principles that underpin the provision of care. Where opportunity cost trade-off figure centrally in the discourse then trials can be justified on the basis of equipoise – genuine uncertainty about which intervention is 'best'. Arguably these concerns are further in the background when the care system is founded on principles of human rights and equality (although still relevant where there are different competing options to achieve these aims). As we have argued, further clarity on these principles will also frame ethical arguments about study designs.

## Using CEA to inform decision making in SC

To achieve greatest benefit (wellbeing) with a CEA approach for decision-making, the most costeffective option is identified for funding first, followed successively by the next best cost-effective options and so forth until the budget is exhausted. Any new and more cost-effective intervention would be funded, displacing the least cost-effective prevailing option. Rather than identify the actual cost-effectiveness level of the latter, a 'cost-effective threshold' is often used in practice to provide this benchmark.

Implementing this approach has conditions, some of which are not currently met in social care. In particular, we identified the following issues.

- There is a need to determine a social care CE threshold (and also associated 'technical' aspects such as discount rates and the need to ensure that marginal cost-effectiveness is calculated relative to next best alternatives). Further evidence about the current marginal cost-effectiveness of social care would help inform the size of the threshold (as the current opportunity cost of social care expenditure). Reference to the threshold used in health care might also be relevant (taking more of a willingness to pay perspective).
- The social care threshold should be specified with a wellbeing outcome indicators that can be combined with health QALYs (to general a single overall CE threshold).

- We need to better understand the outcome implications of interdependency, with health and also with non-publicly funded inputs into social care e.g. informal care.
- Finally, a process is needed to update the threshold to reflect new innovations in care.

A collaboration between sector bodies, representative organisations, the public and the academic community could be formed to address these questions/needs.

### Implementation

The degree which CEA-underpinned guidance is implemented in practice is hard to establish, although it appears modest. Primary evidence (cost-effectiveness evaluations) can directly inform decisions made by commissioners or providers. Alternatively, this evidence can be synthesised in practice guidance by intermediaries. We are seeing a range of initiatives as regards the latter, importantly through NICE and others such as the NIHR-funded ESSENCE project, and the ESRC/Health Foundation-funded IMPACT programme.

Even where evidence is available – including being interpreted to inform decision-making e.g. in the form of NICE guidance – there are potential challenges in having this evidence and guidance adopted by the sector to shape practice. The challenge is multiplied in a system that is characterised by substantial devolvement and de-centralisation of the care delivery and commissioning, with tens of thousands of provider organisations, many in the private sector.

In England NICE, who have been responsible for issuing economic evaluation and guidance for healthcare since 1999, extended this remit to social care in 2013. As another example, the ESSENCE project, coordinated by the Care Policy and Evaluation Centre, showcases a number of case studies and published research on cost-effectiveness on social care. The new IMPACT Centre will also support the implementation of 'evidence of what works' in social care. These initiatives recognise, and are responding to the challenge, of developing practice in social care that is underpinned by evidence. In defining 'evidence' in its broadest form, they also recognise the state of development of the evidence base in social care.

## Concluding comments

We are seeing the evidence base develop, with a range of initiatives and research funding calls, but there are some questions about the application of CEA in social care. These concern: the values and principles that underpin what the (public) care sector is trying to achieve, and in turn what the desired outcomes are for evaluations; how decisions are made in social care using CEA evidence; and finally how the sector can be best supported to implement evidence-based change in practice.

We propose that a debate involving sector bodies, representative organisations, the public and the academic community could help with the first two issues especially, supplemented with research on current opportunity cost levels in social care. In particular, regarding the second concern, further research and consultation is proposed to establish a social care cost-effectiveness threshold and about how to account for spill-over benefits between social care and health systems. Applied implementation research is beginning to cast light on the third issue. Related initiatives are being developed to help to get evidence into social care practice (e.g. the NIHR-funded ESSENCE project, and the ESRC/Health Foundation-funded IMPACT programme, as noted above). Addressing these issues, we argue that CEA can play a greater role and produce significant benefit in the care sector.

## Appendix

Suppose that a social care decision maker (SDM) seeks to maximise social care wellbeing,  $u^s$ , in the population and a health care decision maker (HDM) seeks to maximise health,  $u^h$ . They operate with separate fixed budgets,  $B^s$  and  $B^h$ , respectively. Choices are made about two social care interventions and two health interventions:  $x_1^s$ ,  $x_2^s$  and  $x_1^h$ ,  $x_2^h$ . Total cost (to the budget) of these interventions is given by the functions  $C^s$  and  $C^h$ .

We begin with the SDM's choices, assuming that they are only concerned with social care interventions. The Lagrangian,  $L^s$ , for this maximisation problem is:

$$L^{s} = u^{s}(x_{1}^{s}, x_{2}^{s}) + \lambda^{s} \left( B^{s} - C^{s}(x_{1}^{s}, x_{2}^{s}) \right)$$
(1)

The first order conditions gives the usual equality of the ICER with the CE threshold (here in inverse form i.e.  $\frac{1}{\lambda^s}$  where  $\lambda$  is the Lagrangian multiplier):

$$\frac{u_{x_i^s}^s}{C_{x_i^s}^s} = \lambda^s \tag{2}$$

This implies optimal social care of  $x_i^{s*}$  for i = 1,2. Conventionally, CE thresholds are expressed as the change in cost to achieve a change in outcomes i.e.  $k^s = \frac{1}{\lambda^{s}}$ , for example, an extra £20,000 per QALY gained.

As discussed above, health and social care are interdependent and therefore, health is affected by social care choices i.e.  $u_{\chi_i^S}^h \neq 0$ . With coordination between the DMs, accounting for this interdependency, we have a joint optimisation problem:

$$L^{sh} = u^{s} \left( x_{1}^{s}, x_{2}^{s}, x_{1}^{h}, x_{2}^{h} \right) + u^{h} \left( x_{1}^{s}, x_{2}^{s}, x_{1}^{h}, x_{2}^{h} \right) + \lambda^{s'} \left( B^{s} - C^{s} \left( x_{1}^{s}, x_{2}^{s} \right) \right)$$

$$+ \lambda^{h'} \left( B^{h} - C^{h} \left( x_{1}^{h}, x_{2}^{h} \right) \right)$$
(3)

with first order conditions:

$$\frac{u_{x_i^s}^s + u_{x_i^s}^h}{C_{x_i^s}^s} = \lambda^{s'}$$

$$\tag{4}$$

or

$$\frac{u_{x_i^s}^s}{C_{x_i^s}^s} = \lambda^{s'} - \frac{u_{x_i^s}^h}{C_{x_i^s}^s} = \lambda^{s'} - \mu_i^s < \lambda^{s'}$$
<sup>(5)</sup>

Compared with condition (2) in the separate decision case, and assuming the same fixed (inverse) social care CE thresholds i.e.  $\lambda^{s'} = \lambda^s$ , the criteria from (5) would lead to a different level of social care provision. Indeed, where the optimal level of social care is  $x_i^{s\#}$  from (5), and assuming  $u_{x^sx^s}^s < 0$  and  $C_{x^sx^s}^s \ge 0$ , then for  $\mu_i^s > 0$  we have  $x_i^{s\#} > x_i^{s*}$ .

We have assumed fixed thresholds in this case in line with practice, for illustration, but that would lead to over-spending relative to the budget. Indeed, when accounting for interdependencies, the (inverse) CE thresholds would to change (increase) so that  $\lambda^{s'} > \lambda^s$  (or equivalently  $k^{s'} < k^s$  in cost per QALY terms). With fixed budgets for health and social care, this accounting for interdependencies leads to a different allocation between social care services,  $x_1^s$  and  $x_2^s$ , depending on the relative size of their effect on population health  $(u^h)$ . Were budgets to be pooled in a single fund,  $B = B^s + B^h$ , (and decisions taken jointly) then a single CE threshold could apply, with the condition:  $\frac{u_{x_i}^s + u_{x_i}^h}{c_{x_i}^s} = \lambda = \frac{1}{k}$ . To operate with a single threshold,

that threshold would need to specified with a single overall outcome indicator – in this example,  $u = u^s + u^h$  with  $k = \Delta C / \Delta u$ . In other words, it would require a way to add up (social care) wellbeing and health benefits using a single currency, giving a threshold as, for example, £30,000 per 'well\_health' QALYs. This would also mean that we are prepared to trade-off health and social care wellbeing outcomes between people, i.e. a utilitarian approach, as discussed above.

## References

Aidy, J. E. and Viscusi, W. K. (2008) 'Adjusting the value of a statistical life for age and cohort effects', *Review of Economics and Statistics*, 90(3), pp. 573–581. doi: 10.1162/rest.90.3.573.

Alberini, A. *et al.* (2004) 'Does the value of a statistical life vary with age and health status? Evidence from the US and Canada', *Journal of Environmental Economics and Management*, 48(1), pp. 769–792. doi: 10.1016/j.jeem.2003.10.005.

Apps, J., Crowther, T. and Forder, J. (2013) *Personal outcome measures and postal surveys of social care*. QORU discussion paper, University of Kent. Available at: https://www.pssru.ac.uk/pub/4619.pdf (Accessed: 22 December 2021).

Arons, A. M. *et al.* (2013) 'Quality of life in dementia: A study on proxy bias', *BMC Medical Research Methodology*, 13(1), pp. 1–8. doi: 10.1186/1471-2288-13-110.

Association of Directors of Adult Social Services (2011) *Response by the Association of Directors of Adult Social Services (ADASS) to 2011 inquiry of the All-Party Parliamentary Group on Dementia: How to save money in dementia care and deliver better. Report submitted to Members of Parliament. outcomes for peop.* Available at:

https://www.adass.org.uk/AdassMedia/stories/Press\_Releases\_2011/APPG Dementia Inquiry.doc.

Van Baal, P., Meltzer, D. and Brouwer, W. (2016) 'Future Costs, Fixed Healthcare Budgets, and the Decision Rules of Cost-Effectiveness Analysis', *Health Economics (United Kingdom)*, 25(2), pp. 237–248. doi: 10.1002/hec.3138.

Batchelder, L. *et al.* (2019) 'Carer Social Care-Related Quality of Life Outcomes: Estimating English Preference Weights for the Adult Social Care Outcomes Toolkit for Carers', *Value in Health*, 22(12), pp. 1427–1440. doi: 10.1016/j.jval.2019.07.014.

Beattie, J. *et al.* (1998) 'On the Contingent Valuation of Safety and the Safety of Contingent Valuation: Part 1-Caveat Investigator', *Journal of Risk and Uncertainty 998 17:1*, 17(1), pp. 5–26. doi: 10.1023/A:1007711416843.

Bonell, C. *et al.* (2012) 'Realist randomised controlled trials: a new approach to evaluating complex public health interventions', *Social Science & Medicine*. 2012/09/20, 75(12), pp. 2299–2306. doi: 10.1016/j.socscimed.2012.08.032S0277-9536(12)00639-9 [pii].

Booth, S., Booth, A. and Falzon, L. (2003) 'The need for information and research skills training to support evidence-based social care: a literature review and survey', *Learning in Health and Social Care*, 2(4), pp. 191–201.

Brazier, J. et al. (2014) Eliciting societal preferences for burden of illness, therapeutic improvement and end of life for value based pricing: a report of the main survey. Sheffield. Available at: www.eepru.org.uk (Accessed: 21 December 2021).

Bressan, V., Visintini, C. and Palese, A. (2020) 'What do family caregivers of people with dementia need? A mixed-method systematic review', *Health & Social Care in the Community*, 28(6), pp. 1942–1960. doi: 10.1111/HSC.13048.

Bulamu, N. B., Kaambwa, B. and Ratcliffe, J. (2018) 'Economic evaluations in community aged care: a systematic review', *Bmc Health Services Research*. 2018/12/15, 18(1), p. 967. doi: 10.1186/s12913-018-3785-310.1186/s12913-018-3785-3 [pii].

Cameron, D., Ubels, J. and Norström, F. (2018) 'On what basis are medical cost-effectiveness thresholds set? Clashing opinions and an absence of data: a systematic review', *Global health action*, 11(1). doi: 10.1080/16549716.2018.1447828.

Care Policy and Evaluation Centre (no date) *The Essence Project*. Available at: https://essenceproject.uk/ (Accessed: 21 December 2021).

Care Quality Commission (2017) *The Adult Social Care Key Lines of Enquiry and Prompts: Sources of evidence*. Available at: https://www.cqc.org.uk/sites/default/files/20171020-adult-social-care-kloes-prompts-and-characteristics-showing-changes-final.pdf (Accessed: 21 December 2021).

Charlton, V. (2021) 'Does NICE apply the rule of rescue in its approach to highly specialised technologies?', *Journal of Medical Ethics*, 0, pp. 1–8. doi: 10.1136/medethics-2020-106759.

Chilton, S. et al. (2020) A scoping study on the valuation of risks to life and health: the monetary value of a life year (VOLY) Final report. Available at:

https://www.gov.uk/government/publications/valuation-of-risks-to-life-and-health-monetary-value-of-a-life-year-voly/a-scoping-study-on-the-valuation-of-risks-to-life-and-health-the-monetary-value-of-a-life-year-voly (Accessed: 21 December 2021).

Claxton, K. *et al.* (2011) 'Discounting and decision making in the economic evaluation of health-care technologies', *Health Economics*, 20(1), pp. 2–15. doi: 10.1002/hec.1612.

Claxton, K. *et al.* (2015) 'Methods for the estimation of the National Institute for Health and care excellence cost-effectiveness threshold', *Health Technology Assessment*, 19(14), pp. 1–503. doi: 10.3310/hta19140.

Coast, J. *et al.* (2008) 'An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people', *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*, 17(7), pp. 967–976. doi: 10.1007/S11136-008-9372-Z.

Cookson, R., McCabe, C. and Tsuchiya, A. (2008) 'Public healthcare resource allocation and the Rule of Rescue', *Journal of Medical Ethics*, 34(7). doi: Artn 540Doi 10.1136/Jme.2007.021790.

Detering, K. M. *et al.* (2010) 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial', *BMJ*, 340(7751), p. 847. doi: 10.1136/BMJ.C1345.

Detsky, A. S. and Naglie, I. G. (1990) 'A clinician's guide to cost-effectiveness analysis', *Annals of Internal Medicine*, 113(2), pp. 147–154. doi: 10.7326/0003-4819-113-2-147.

Flynn, T. N. *et al.* (2011) 'Assessing quality of life among British older people using the ICEPOP CAPability (ICECAP-O) measure', *Applied Health Economics and Health Policy*, 9(5), pp. 317–329. doi: 10.2165/11594150-00000000-00000.

Forder, J. (2009) 'Long-term care and hospital utilisation by older people: An analysis of substitution rates', *Health Economics*, 18(11), pp. 1322–1338. doi: 10.1002/hec.1438.

Forder, J. *et al.* (2018) 'The impact of long-term care on quality of life', *Health Economics (United Kingdom)*, 27(3), pp. e43–e58. doi: 10.1002/hec.3612.

Forder, J. E. and Caiels, J. (2011) 'Measuring the outcomes of long-term care', *Social Science and Medicine*, 73(12), pp. 1766–1774. doi: 10.1016/j.socscimed.2011.09.023.

Forder, J. and Fernandez, J. (2015) *Using a 'wellbeing' cost-effectiveness approach to improve resource allocation in social care*. Canterbury: PSSRU, Universituy of Kent. Available at: http://www.pssru.ac.uk/publication-details.php?id=4956.

Forder, J., Gousia, K. and Saloniki, E. C. (2019) 'The impact of long-term care on primary care doctor consultations for people over 75 years', *European Journal of Health Economics*, 20(3), pp. 375–387. doi: 10.1007/s10198-018-0999-6.

Gillies, C. *et al.* (2016) Advancing quantitative methods for the evaluation of complex interventions. NIHR Journals Library. doi: 10.3310/HSDR04160-37.

Gray, M. *et al.* (2014) 'Opinions about evidence: a study of social workers' attitudes towards evidence-based practice', *Journal of Social Work*, 14(1), pp. 23–40. doi: 10.1177/1468017313475555.

Harms-Smith, L. *et al.* (2019) *Social Work and Human Rights: A Practice Guide*. Available at: https://www.basw.co.uk/system/files/resources/Social Work and Human Rights A Practice Guide. DEC 2019.pdf (Accessed: 22 November 2021).

Higgins, R., Oldman, C. and Hunter, D. J. (1994) 'Working together: lessons for collaboration between health and social services', *Health & Social Care in the Community*, 2(5), pp. 269–277. doi: 10.1111/J.1365-2524.1994.TB00174.X.

HM Treasury (2018) *The Green Book. Central Government Guidance on Appraisal and Evaluation, HM Treasury: London.* Available at: www.gov.uk/official-documents (Accessed: 6 August 2021).

Johannesson, M. and Weinstein, M. C. (1993) 'On the Decision Rules of Cost-Effectiveness Analysis', *Journal of Health Economics*, 12(4), pp. 459–467.

Jonsen, A. R. (1986) 'Bentham in a box: technology assessment and health care allocation.', *Law, medicine & health care : a publication of the American Society of Law & Medicine*, 14(3–4), pp. 172–174. doi: 10.1111/j.1748-720x.1986.tb00974.x.

Laing, W. (2019) Care homes for older people UK market report. London.

Laska, E. M. *et al.* (1999) 'Ratio-based and net benefit-based approaches to health care resource allocation: Proofs of optimality and equivalence', *Health Economics*, 8(2), pp. 171–174. doi: 10.1002/(SICI)1099-1050(199903)8:2<171::AID-HEC424>3.0.CO;2-E.

Van Leeuwen, K. M. *et al.* (2015) 'Comparing measurement properties of the EQ-5D-3L, ICECAP-O, and ASCOT in frail older adults', *Value in Health*, 18(1), pp. 35–43. doi: 10.1016/j.jval.2014.09.006.

Levin, H. M. and McEwan, P. J. (2001) *Cost-effectiveness analysis: Methods and applications. (2nd ed.).* Thousand Oaks, CA: SAGE Publications Inc.

Longo, F. *et al.* (2021) 'Does public long-term care expenditure improve care-related quality of life of service users in England?', *Health Economics (United Kingdom)*, 30(10), pp. 2561–2581. doi: 10.1002/HEC.4396.

Lowry, R. and Peterson, M. (2011) 'Cost-benefit analysis and non-utilitarian ethics':, *http://dx.doi.org/10.1177/1470594X11416767*, 11(3), pp. 258–279. doi: 10.1177/1470594X11416767.

Makai, P. *et al.* (2014) 'Quality of life instruments for economic evaluations in health and social care for older people: A systematic review', *Social Science and Medicine*, pp. 83–93. doi: 10.1016/j.socscimed.2013.11.050.

Marseille, E. and Kahn, J. G. (2019) 'Utilitarianism and the ethical foundations of cost-effectiveness analysis in resource allocation for global health', *Philosophy, Ethics, and Humanities in Medicine 2019 14:1*, 14(1), pp. 1–7. doi: 10.1186/S13010-019-0074-7.

McCabe, C., Claxton, K. and Culyer, A. J. (2012) 'The NICE Cost-Effectiveness Threshold', *PharmacoEconomics 2008 26:9*, 26(9), pp. 733–744. doi: 10.2165/00019053-200826090-00004.

Netten, A. *et al.* (2012) 'Outcomes of social care for adults: developing a preference-weighted measure', *Health Technology Assessment*, 16(16), pp. 1–166. doi: Doi 10.3310/Hta16160.

NICE (2011) *Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease: Technology appraisal guidance*. London.

NICE (2013) *Guide to the methods of technology appraisal*. London. Available at: https://www.nice.org.uk/process/pmg9/resources/guide-to-the-methods-of-technology-appraisal-2013-pdf-2007975843781.

NICE (2019a) NICE impact adult social care. London.

NICE (2019b) *Position statement on use of the EQ-5D-5L value set for England*. London. Available at: https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/technology-appraisal-guidance/eq-5d-5l (Accessed: 21 December 2021).

NICE (2020) *The NICE methods of health technology evaluation: the case for change*. London. Available at: https://www.nice.org.uk/Media/Default/About/what-we-do/our-programmes/nice-guidance/chte-methods-consultation/NICE-methods-of-health-technology-evaluation-case-for-change.docx.

NICE (2021) *Our principles*. London. Available at: https://www.nice.org.uk/about/who-we-are/our-principles (Accessed: 21 December 2021).

Paulden, M. (2017) 'Recent amendments to NICE's value-based assessment of health technologies: implicitly inequitable?', *Expert Review of Pharmacoeconomics and Outcomes Research*. Expert Rev Pharmacoecon Outcomes Res, pp. 239–242. doi: 10.1080/14737167.2017.1330152.

Rand, S. *et al.* (2017) 'Developing a proxy version of the Adult social care outcome toolkit (ASCOT)', *Health and Quality of Life Outcomes*, 15. doi: ARTN 10810.1186/s12955-017-0682-0.

Rand, S. and Caiels, J. (2015) *Using Proxies to assess Quality of Life: A Review of the Issues and Challenges*. Canterbury. Available at: www.qoru.ac.uk (Accessed: 21 December 2021).

Rand, S. E. *et al.* (2015) 'Factor structure and construct validity of the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer)', *Quality of Life Research*, 24(11), pp. 2601–2614. doi: 10.1007/s11136-015-1011-x.

Rand, S., Forder, J. and Malley, J. (2017) 'A study of dyadic interdependence of control, social participation and occupation of adults who use long-term care services and their carers', *Quality of Life Research*, 26(12), pp. 3307–3321. doi: 10.1007/s11136-017-1669-3.

Rand, S., Malley, J. and Forder, J. (2019) 'Are reasons for care-giving related to carers' care-related quality of life and strain? Evidence from a survey of carers in England', *Health & Social Care in the Community*, 27(1), pp. 151–160. doi: 10.1111/hsc.12634.

Roland, D., Forder, J. and Jones, K. (2021) 'What Is Out There and What Can We Learn? International Evidence on Funding and Delivery of Long-Term Care', *Social Policy and Society*, pp. 1–14. doi: 10.1017/S1474746421000531.

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(4), pp. 389–399. doi: 10.1007/S10198-013-0482-3/FIGURES/1.

Shaw, S., Rosen, R. and Rumbold, B. (2011) *What is integrated, Integration The VIsi Journal*. Available at: www.nuffieldtrust.org.uk/integratedcare (Accessed: 21 December 2021).

Smith, N. *et al.* (2019) 'Encouraging managers of care homes for older adults to participate in research', *Quality in Ageing and Older Adults*, 20(3), pp. 120–129. doi: 10.1108/QAOA-04-2019-0017.

Smith, S. et al. (2013) 'Evidence on the cost and cost-effectiveness of palliative care: A literature

review', *Palliative Medicine*, 28(2), pp. 130–150. doi: 10.1177/0269216313493466.

Stevens, K., Brazier, J. and Rowen, D. (2018) 'Estimating an exchange rate between the EQ-5D-3L and ASCOT', *European Journal of Health Economics*, 19(5), pp. 653–661. doi: 10.1007/s10198-017-0910-x.

Teno, J. M. *et al.* (2004) 'Family perspectives on end-of-life care at the last place of care', *JAMA*, 291(1), pp. 88–93. doi: 10.1001/JAMA.291.1.88.

Towers, A. M. *et al.* (2019) 'A cross-sectional study exploring the relationship between regulator quality ratings and care home residents' quality of life in England', *Health and Quality of Life Outcomes*, 17(1), pp. 1–11. doi: 10.1186/s12955-019-1093-1.

Watters, S. (2015) 'The Rule of Rescue: An investigation into age-related preferences and the imperative to save a life':, *http://dx.doi.org/10.1177/1477750915588891*, 10(3), pp. 70–79. doi: 10.1177/1477750915588891.

Weatherly, H. *et al.* (2017) *Scoping Review on Social Care Economic Evaluation Methods*. Centre for Health Economics, University of York.

Wright, A. A. *et al.* (2008) 'Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment', *JAMA*, 300(14), pp. 1665–1673. doi: 10.1001/JAMA.300.14.1665.