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Christopher James Sampson\*

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\*Correspondence to: C J Sampson, Division of Rehabilitation and Ageing, University of Nottingham, Queen's Medical Centre, Nottingham, NG7 2UH, UK  
[chris.sampson@nottingham.ac.uk](mailto:chris.sampson@nottingham.ac.uk)

# Identifying objects of value at the end of life

Christopher J Sampson<sup>1</sup>

1. Division of Rehabilitation and Ageing, School of Medicine, University of Nottingham,  
Queen's Medical Centre, Nottingham NG7 2UH, UK

# Introduction

As end of life care rises up the political and research agenda, methods of economic evaluation are coming under increased scrutiny from researchers both inside and outside of the health economics field. Such scrutiny is warranted – end of life care has a number of characteristics that make economic evaluation particularly challenging. These include: proximity to death, the improbability of survival gain, individuals' changing priorities, declining cognition and effects on close persons (for a fuller discussion of these issues, see Chapter 2). In view of these particularities of end of life care, some researchers have determined that current 'extra-welfarist' approaches to defining outcomes – in terms of quality-adjusted life years (QALYs) – do not adequately reflect well-being. As a result, suggestions are being made that would see the QALY approach either replaced or subject to significant redefinition.

In relation to end of life care the debate is still in its infancy, with few substantive discussions about appropriate outcome measurement for the purpose of resource allocation. A number of alternatives have been proposed, most notably the capability approach and the palliative care yardstick (PaLY) framework [1–3]. The purported goal of adopting these alternative evaluation approaches is to extend the evaluative space 'beyond health' - that is, to include non-health outcomes when considering the benefits of interventions in economic evaluations. In addition to these proposed alternative frameworks, more specific aspects of life that are not currently considered within the evaluative space, such as the 'provision of a good death' or 'being treated with dignity', have also been suggested for explicit consideration in the evaluation process (though it is not immediately clear how - or why - these items should be counted in economic evaluation).

The purpose of this chapter is to guide the definition of what should be included in the evaluative space in end of life care, but also more broadly. I consider which outcomes – what Sen has called 'objects of value' – might be included within an economic evaluation, in relation to *what* we value (the domains) and *why* we value it (its consequents). My focus is upon judgements about the effectiveness of interventions in end of life care, rather than issues surrounding equity or decision criteria in the allocation of resources. Such issues are discussed elsewhere in this volume (see for example Chapters 9 and 10 ). I argue that alternative evaluative frameworks are currently ill-defined. I identify some gaps in the apparent normative foundations of these alternative approaches and some flaws in the operational proposals that arise in efforts to implement the alternative frameworks. Finally, I consider some criticisms of the use of QALYs but suggest that current approaches should be maintained, with some changes.

## Objects of value

Central to this discussion is the identification of 'objects of value'. Objects of value are those items that we might wish to consider in an evaluation, and which might be influenced by interventions in end of life care or other health care settings. They might include such objects as being free from pain, being worried, owning a TV, having independence, being fertile, or being in employment. Some objects of value might be easily

observable, while others may be intangible. There is no limit to the number of possible objects of value, but we might have reason to believe that not all objects are worthy of consideration. There may be some potential effects of interventions (whether positive or negative) that we might not want to include in an analysis. For example, we might wish to exclude income from employment as an object of value (even if people seek to maximise their incomes) either because we do not consider it an end in itself or because it is not relevant to the context of health and social care. This therefore raises the inevitable question of which objects of value should be included.

Taken together, the objects of value that are considered in an analysis define the evaluative space of the economic evaluation. Because any aspect of a person's life experience could potentially be included as an object of value, the sum of all potential objects of value defines a person's state of being. Those objects that we determine to be of value to the individual define their well-being. In this chapter I provide some guidance on the process of identifying objects of value. Failure to appropriately identify which objects of value should be included in the evaluative space could result in inefficient and inequitable allocations of resources.

### **The meaning of extra-welfarism**

The cost-per-QALY approach currently used in the UK and elsewhere has become known as extra-welfarism. Much debate has taken place (and continues) around the definition of extra-welfarism. In this chapter I take at face value the definition provided by Brouwer et al[4]. This is a broad conception of extra-welfarism and, generally speaking, proponents of alternative approaches to economic evaluation in end of life care do not completely reject it. Therefore, I interpret these alternatives as (potentially) representing adjustments to the evaluative space within the scope of extra-welfarism.

Tony Culyer - one of the key architects of extra-welfarism in health economics - has discussed the notion of 'characteristics of people' and identifies these as the objects of value within the extra-welfarist evaluative space [5]. Characteristics of people include such notions as 'being able to feed oneself' and 'being reassured'. In this vein, Brouwer et al suggest "characterizing the evaluative space of extra-welfarism... as an assembly of other characteristics of individuals"[4]. However, while this limits the evaluative space to characteristics of people (rather than resources or their characteristics), it does not determine whether all characteristics of people should be included within the evaluative space or how one might identify specific characteristics of people to consider. Hurley states that part of the extra-welfarist evaluation process is to, "from the set of all characteristics of people, define the set of characteristics that are normatively relevant for evaluation in the health sector"[6]. In this chapter I present a means of more clearly defining the evaluative space within such an extra-welfarist framework.

## Domains and consequents: the what and why of the evaluative space

Sen identifies two questions in regard to evaluation: i) what are the objects of value and ii) how valuable are these respective objects. He describes the former as defining the 'evaluative space' [7], and it is this question that is explored throughout this chapter.

Here I present reason and basis for demarcation in the definition of the evaluative space, adding the question of *why* particular objects are valuable to Sen's questions of *what* is valuable and *how valuable* it is. These are normative questions, and researchers should define objects of value in terms of what I will call 'domains' – the *what* of the evaluative space – and their 'consequents' – the *why*.

### Definitions

#### Domains

Domains are those realms of human life in which we would deem improvements to be valuable. There is no limit to the number, scope or specificity of domains that might be included within the evaluative space, but each needs clear justification. Domains are not mutually exclusive and might have any number of subdomains across physical, psychological and spiritual constructs. A domain of particular relevance in the economic evaluation of health care is health. Other examples might include mobility, employment, nourishment, autonomy, relationships or any other aspect of life that we think might be relevant and worthy of consideration.

#### Consequents

Consequents have not previously been specified in the literature. They represent *in what respect* we value particular objects. That is, they are the reason *why* we value states within domains and are the means by which well-being (in its broadest sense) might be improved<sup>1</sup>. Consequents represent the consequential effect on well-being (however understood) of a given state, not the consequential result of a particular intervention. Relevant consequents to economic evaluation in health care might include (though are not limited to):

- capabilities [8]
- functionings [8]
- preference satisfaction [9]
- general satisfaction [10]
- need satisfaction [11]

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<sup>1</sup> Use of the term 'consequent' should not be understood to imply consequentialism, the notion that the outcomes of actions are the basis by which to judge the moral correctness of those actions.

Consequents are not necessarily mutually exclusive. Individual preferences might be valued in their own right as a consequent, or might be used as a proxy for utility (another consequent), while both might also reflect changes in capability sets. However, this does not mean that these are equivalent or that the choice of consequents is - for lack of a better word - inconsequential. What is important is the extent to which each approach adequately reflects the value provided by a state. For example, a wide choice set may be valuable to a person but not adequately reflected in their preferences. This is one of the primary arguments in favour of adopting capabilities as the consequent of value, because adaptation might lead to people's preferences not adequately reflecting the value associated with particular capability sets.

Later I will discuss means of identifying which domains and consequents should be included in the evaluative space and the extent to which different approaches are explicit in their attempts to do so. For now it will suffice to acknowledge that we *might* not want to include all possible domains or consequents within the evaluative space.

### **Defining the evaluative space**

A substantial philosophical literature has developed around the notion that 'health' holds special moral significance [47], and similar ideas have developed in the context of economic evaluation in health care. Consider the often repeated claim made in the extra-welfarist literature that 'health' is something that is valuable *as an end in itself* [11]. Such a claim requires some working definition of health, and any useful definition (that is, useful as an objective) necessarily relates to particular consequents. One cannot attach value in the absence of definition. Even the most rudimentary definitions of health (consider 'not dead') necessitate a level of functioning as a consequent, even if not explicitly acknowledged. Some definitions of health imply capabilities as the consequent – for example that of Huber et al who propose the inclusion of adaptation and self-management as key components of health. [12]

Consider mobility as a possible object of value within the domain of health. If our concern lies in the extent to which people are mobile, then the consequent is functioning. If we primarily care about whether or not an individual prefers a given state of mobility, then individual preferences are the consequent. Valuations of these different objects of value might not be equal, and therefore it is important to define in what respect mobility should be included within the evaluative space. The fundamental notion of mobility cannot itself be an object of value (rather, 'mobility' should be considered a domain). Likewise, the notion of health cannot be an object of value. Objects of value might include being in good health, having the opportunity to be in good health, or being satisfied with one's health.

Superficially, it might seem reasonable to equate the domains of the evaluative space with specific descriptive systems, while equating the consequents of the evaluative space with specific valuation methods. However, this would be an error. Descriptive systems (e.g. questionnaires) should be developed such that they provide

maximum informational content (as is feasible) regarding objects of value within the domains of interest. Attention should also be given to the number of states that the descriptive system is able to define, and practical concerns associated with this [13]. Valuation methods should seek to quantify the value of the objects in respect to the consequents. Backward reasoning could lead to misspecification of the evaluative space. Both consequents and domains require ex ante definition in order to avoid this. The conflation of consequents and domains is also common. For example, the 'outcome' of welfarist approaches is usually seen to be utility while the 'outcome' of extra-welfarism is seen to be health. In this sense each has been interpreted as 'unidimensional' [6]. But utility (as a consequent) and health (as a domain) are not comparable in this way<sup>2</sup>.

Sen states that "the selection of the evaluative space has a good deal of cutting power"[7], highlighting the importance of clarity in this regard. Failure to clearly define the evaluative space risks including and excluding the wrong objects of value, even in terms of one's own normative position. Extra-welfarism adopts 'characteristics of people' as the objects of value. We can now acknowledge that characteristics of people require definition in terms of both consequents and domains. Consider one example characteristic highlighted earlier in this chapter – being able to feed oneself [5]. The wording "being able to" implies that this characteristic is valued as a capability, invoking this as the primary (if not exclusive) consequent of interest. "To feed oneself" could be a specific domain of interest, though it seems to imply a domain of autonomy. Thus we could determine that the evaluative space consists the domain of autonomy, valued in respect to the capabilities provided by objects within this domain. However, we could alternatively conclude that this characteristic is of value in terms of health functionings. This retro-fitting approach is problematic in at least two ways. First, it can be used to justify any number of domains and consequents being included in the evaluative space. The reason for including this characteristic remains unknown, and it becomes impossible to establish boundaries to the evaluative space. Second, we cannot know the informational value of these objects as indicators of well-being and thus their use in evaluation presupposes usefulness. Objects with more informational value within the domain may remain unidentified. As such, the objects may be given undue weight.

## **Normative positions**

Which domains and consequents should be included in the evaluative space is an unavoidable normative question that cannot be answered exclusively by empirical investigation. There is much discussion both within and beyond health economics about definitions of well-being and recommended normative positions. In general, researchers have tended to focus either on the consequents of value or on the domains of value, while being unclear regarding the other. For example, Sen clearly argues in favour of capabilities, while being

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<sup>2</sup> Furthermore, determining a single metric for outcome measurement is a feature of the decision rules employed and does not necessitate a unidimensional evaluative space.

reluctant to specify domains[14]. Conversely, Rawls's 'primary goods' clearly outline a set of domains while being unclear about in what respect resources are valued[15] – though one interpretation of Rawls's later writing could be that he accepted capabilities as the consequent of value, stating that Sen's idea is "needed to explain the propriety of the use of primary goods" [16]. A strict welfarist could be an exception in clearly defining the consequent (individual utility) and valuing all domains (as might be represented in a simple willingness to pay exercise). Martha Nussbaum is another exception in clearly defining capabilities as the consequent and a narrow set of 'central capabilities' (including bodily health, emotions and practical reason) as domains[17].

Some authors have discussed the idea of 'context' in the capabilities literature[8]. The context of evaluation being discussed here is health care or, more specifically, end of life care. Depending on an individual's normative position, the context of the evaluation might or might not be allowed to inform the selection of domains. Later I argue that it should.

## New vistas for extra-welfarism in end of life care?

Having specified the basis on which the evaluative space should be defined (i.e. in terms of domains and consequents), we can now explore the extent and manner in which alternative frameworks for economic evaluation in end of life care expand the evaluative space as they claim. In this section I consider the health-related QALY approach and its alternatives. For each I consider the supposed normative basis of the approach and the consistency and validity in its application – both generally and with specific reference to end of life care – and assess to what extent each determines a different evaluative space. Because it has undergone the most development in the health economics literature, my focus will be upon the capabilities approach. Definitions of extra-welfarism have been widely discussed[4, 6, 18, 19]. Here I simply wish to assert that extra-welfarism is an ambiguous concept. The alternatives presented herein are considered broadly within the realm of extra-welfarism. While some have described cost-per-QALY analysis as non-welfarist[20], whether a given evaluative space should or should not be considered extra-welfarist is not the subject of this chapter.

### Health-related QALYs

Extra-welfarism (as currently operationalised) is commonly described as involving 'health maximisation' [21]. Indeed, a focus on the domain of health might be considered extra-welfarism's defining feature, at least as the term is currently used [21]. Extra-welfarism has been criticised as restrictive on this basis, though clear definition of the domains of the evaluative space should be seen as a positive feature of an evaluative framework.

In terms of consequents, the health-related QALY framework is less well defined. There is little agreement in the literature over the principal consequent, even in the narrow understanding of extra-welfarism as health



maximisation. There are at least 3 interpretations of the consequent. First, current QALY approaches might capture health preferences, with preferences over health states as the consequent. This is perhaps the most common understanding of the QALY approach, with the use of valuation tools that explicitly seek to elicit preferences and economic evaluations using QALYs described as 'cost-utility' analyses. Preference elicitation techniques are variously considered to elicit von Neumann-Morgenstern utility or some other form of choice value. As such, the 'preference satisfaction' understanding of the health-related QALY approach could further be interpreted in multiple ways. Second, QALYs might be interpreted as measuring health functionings, using tools such as the EQ-5D. This view is presented by some critics of the health-related QALY, in particular proponents of the capabilities approach[22]. Third, it is possible to interpret QALYs as capturing capabilities[23].

In using the health-related QALY, the evaluative space consists of the domain of health. As such, end of life care is only deemed effective to the extent that improvements are observed within the domain of health. However, in practice, some measurement tools have been designed such that they allow for a very broad understanding of health. For example, the EQ-5D includes the dimension 'usual activities', which might be considered beyond the domain of health in some respects (though when completing the questionnaire respondents are asked to consider their answers in respect of their health). Such ambiguities arise because the evaluative space was not clearly defined and used to guide the development of such descriptive systems.

Though there are problems associated with the health-related QALY approach - some solutions for which I outline below - it can be used to evaluate end of life care with respect to objects of value that lie within the domain of health[1]. Due to ambiguity in the consequent associated with the health-related QALY approach, there is scope for reinterpretation and minor adjustment to satisfy researchers' preferred normative position in this regard. However, if objects of value outside the domain of health are to be included then an alternative approach is necessary. Later I argue that such a change is unwarranted and undesirable.

## **Capabilities**

One major claim, currently gaining traction in end of life care, is in favour of the capability approach. Introduced by Sen[8], the capability approach proposes a movement away from an understanding of well-being as 'utility' towards the acknowledgement of functionings (what people are and what they do) and capabilities (the alternative sets of functionings available to a person), with capabilities forming the basis of the evaluative space. The apparent focus of the capability approach is therefore on defining the evaluative space by an alternative consequent. In health economics it has been characterised as a shift in focus "away from achieved functionings towards the freedom that a person has in their lives to achieve different aspects of well-being"[24]. Such a capability approach has also been described as offering a means of finding balance between autonomy and paternalism[25]. However, as suggested above, health-related QALYs might already be

interpreted as reflecting capability sets[23]. Therefore, we must consider what proponents seek to add beyond a simple reinterpretation.

In practice, the focus of the capability approach in health economics has been upon extending the evaluative space to include additional domains of value, rather than its namesake consequent. It has been framed as an “extension of the informational or evaluative space”[24] that offers a broader understanding of well-being [26]. What people prioritise as being important to their quality of life changes as they approach the end of life[27], and this is perhaps the primary reason for the suggestion of alternative outcome measures in end of life care. Proponents have suggested that capabilities better reflect what is important to people at the end of life, and there is some evidence that people in end of life care do value capabilities [28] (though it is not clear to what extent they are valued in relation to alternative consequents such as functionings). An effort to more accurately capture the capabilities associated with particular states - if we determine these to lie within the evaluative space - is a valuable exercise.

Specific objects of value have been identified in relation to end of life care (e.g. ‘preparing for death’, ‘receiving spiritual comfort’, ‘being treated with dignity and respect’, ‘influencing the care received’, ‘receiving love and support’, ‘not feeling like a burden’ and ‘achieving a sense of completion in life’ [2]), and these have been presented as relating to capabilities. However, such objects might also be defined in terms of functioning (e.g. ‘did people say goodbye and make preparations?’). The relevance of capabilities is presupposed in the wording of these characteristics. The key distinction being made is not in the objects of value but in the way the question is presented. By extension, objects of value in the EQ-5D could be rephrased to represent capabilities – e.g. “I have some problems washing or dressing myself” becomes “If I want to, I am able to wash or dress myself as I need”. Such retrofitted arguments in favour of a capabilities approach should be avoided.

There has also been some suggestion that the capability approach in end of life care might be used to justify existing interventions based on their objectives. For example, Coast highlights that “the objective of care at the end of life is not focused purely on health improvement” [2] and presents this as an argument against current approaches. Here, again, the tail is wagging the dog. What care currently tries to achieve may be entirely misguided and is irrelevant to the definition of the evaluative space.

One specific argument in favour of a capability approach in end of life care has focused on the opportunity for a good death[2, 3]. It remains unclear why ‘a good death’ should necessarily indicate capabilities as the consequent of interest, and its explicit inclusion risks skewing evaluations away from what patients and the public value. There is no clear definition of to which aspects of life (domains) the provision of a good death brings value, and no explanation of how it relates to the consequent of capabilities. Regardless, as discussed previously, this retrofitting approach to particular proposed objects of value precludes the definition of the evaluative space. This is not to say that the provision of a good death should not be considered, but rather that it is not the place of economists to specify items at their will. Suppose that ‘opportunity for a good death’ is

identified as being a relevant aspect of the health domain and that we value the capabilities associated with it as a consequent. It does not follow that this should be *the* or even *a primary* object of value identified through outcome measurement. There may be many more important objects of value that might better reflect well-being and provide more information about the evaluative space. Unless this object of value is identified as a relevant indicator within a predefined evaluative space, its inclusion risks misrepresenting patients' priorities and resulting in inefficient allocations of resources.

Aside from the examples cited above, proponents of the capabilities approach are developing improved methods for the development of descriptive systems to reflect a pre-specified evaluative space[29–31]. These qualitative approaches are designed such that they elicit information about the most important and informative objects of value within an evaluative space for a given sample. This is in contrast to the methods used to develop health-related preference-based measures such as the EQ-5D, which was based on an assessment of pre-existing instruments[32] (though improved approaches are being developed for health-related preference-based measures[33]). However, it is not clear how one might determine whether particular objects of value are identified because of their importance as a capability or because of their importance as an achieved functioning[34].

Coast has argued that health maximisation is not always important, including in end of life care, arguing that individual choice is more important[2]<sup>3</sup>. This claim seems to confuse domains (health) with consequents (individual choice) in the context of a decision rule (maximisation), and inexplicably introduces choice alongside the previously discussed consequent of capabilities. Sen has rejected the choice approach to well-being[8], and it is difficult to see how the capability approach could be used to justify prioritisation of individual choice in end of life care. The reason Sen opposes the choice approach is that individual choice probably does not adequately reflect capabilities. In this regard, a focus on individual choice would seem to contradict the purpose of the capabilities approach and instead support the use of individual preferences as the consequent.

## MEASURING CAPABILITIES

The ICECAP family of measures - which purport to capture capabilities - have adopted best-worst scaling and discrete choice experiments for the purpose of valuation. Those involved in the design of ICECAP instruments argue that best-worst scaling might reflect 'values' rather than preferences and therefore be appropriate in capturing capabilities, meanwhile claiming that best-worst scaling is an effective method for capturing utility [35, 36]. This raises the question of whether proponents of such measures make any distinction between the

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<sup>3</sup> Here I have understood 'choice' in terms of the act of making a choice, which clearly relates to the notion of preferences and is a consequent. However, it might also be interpreted (and it may be Coast's intention to present it) as freedom or autonomy, which should be considered a domain. Thanks to Alastair Canaway for highlighting this.

two consequents of capabilities and preference satisfaction and - if they do not - why they seek to adjust the consequent of the evaluative space. This obscures the basis for a rejection of the normative foundations of QALYs, which - as already noted - could be interpreted as reflecting capabilities. These approaches are only likely to capture capabilities to the extent that they are reflected by preferences, undermining their purpose.

Recently, the ICECAP Supportive Care Measure (ICECAP-SCM) has been developed for the purpose of evaluating end of life care, based on the factors that older people (at the end of life) consider important [31]. In eliciting objects for inclusion, no evaluative space was clearly pre-defined. Respondents were not asked about attributes relating to a specific domain, such as health. As such, all of those objects of value that were identified (namely; 'having a say', 'being with people who care about you', 'physical suffering', 'emotional suffering', 'dignity', 'being supported' and 'being prepared') come from an unbounded evaluative space. The first thing to conclude from this is that the measure cannot be directly comparable on equivalent scales - however valued - to a measure based on a restricted evaluative space. This is because the measures are likely to provide information about different constructs; one could not equate information about a person's satisfaction with health with information about their subjective well-being. Indeed, the ICECAP-SCM is not presented as - or intended to be - comparable with measures such as the EQ-5D. Rather, it might be used to achieve technical efficiency - not allocative efficiency - within the restricted context of end of life care. This is in contrast to the approach adopted in the recent development of the CHU9D - a paediatric preference-based outcome measure - which asked specifically about health; thus restricting the domain and ensuring comparability in terms of the evaluative space [33].

In relation to end of life care, Coast argues that "death itself may not imply a loss of capability"[2]. However, this creates a conundrum when we observe the approach to valuation that has been applied to the capabilities approach in health economics. Measures like the ICECAP-O assume that the lower boundary of value is 'no capabilities', and also that being dead equates to having no capabilities. Thus, 'dead' cannot be assigned a higher value than any other state and the only state compared to which death might not represent a loss of capability is that in which an individual already has no capability.

By accepting conveniences in the operation of the capability approach, the family of ICECAP measures may be reduced to little more than a semantic nuance; their focus being on the use of terms such as "I am able to", "I can" and "If I want to". There may be merit in this, but there is currently no evidence to suggest that the use of these terms results in any substantive difference in response. A simple test could involve comparing two questionnaires - one using functioning terms (e.g. 'I am', 'I do') and the other using capability terms (e.g. 'I am able to', 'I can') - that are identical except in their wording, and to see if individuals either a) give divergent responses or b) attach different values to states defined in these terms. Advocates of the capability approach are keen to allow time for further development of measures [24], which could prove fruitful.

As currently presented in relation to end of life care, the capabilities approach seems unclear and insufficiently justified. Its primary goal in health economics appears to be to extend the evaluative space 'beyond health'. Therefore, (somewhat confusingly) the capabilities approach indicates changes in the domains of interest rather than necessarily changes in the consequents. The ways in which researchers have operationalised the approach to date support this view. This movement 'beyond health' rather than towards capabilities has received less discussion and there have been fewer arguments provided in favour of such an extension to the evaluative space<sup>4</sup>. The primary nature of the capabilities argument against health-related QALYs is to extend the domains of the evaluative space from health alone to well-being more broadly, and this view has - for reasons that are not clear - become conflated with a movement towards valuing capabilities rather than functionings.

### **Other alternatives**

Normand presents an argument against the use of 'standard' outcome measures in end of life care, suggesting that 'contextual factors' may be important [3]. This, to some extent, echoes the claims for inclusion of specific objects of value within the evaluative space and is subject to the same errors in reasoning. The more fundamental suggestion by Normand is that the value of time may not be constant and thus the additive assumption of the QALY may not hold. Normand argues that this is particularly relevant at the end of life, when time is limited. The resulting framework proposed is the Palliative Care Yardstick (PaY)[3, 38], which involves two changes to the standard QALY approach. First, additional items would be added in that might not otherwise be adequately measured. Second, non-additivity of time should be accepted. Normand suggests that non-additivity of time might be achieved by allowing value to be attached to the components of a 'good death'. In regard to the first suggestion, this approach is flawed insofar as it requires the retrofitting approach previously described. If followed, investigators might adopt similar methods to those used for establishing 'bolt-on' items for preference-based measures[39]. The second suggestion seems to conflate two separate issues – the non-additivity of time (e.g. greater weight to years immediately preceding death) and the value of a good death (i.e. differential objects of value).

Time exists separately to the evaluative space because it does not define an individual's state of being, and its role should therefore be defined in the valuation process. Current approaches assume that value is additive in time; e.g. that 2 years in a given state is of twice as much value as 1 year in that state. It seems intuitively true that time is more valuable at the end of life because it is more scarce – when a person dies, their time has run out. In this respect, the PaY is not based on any adjustment of the evaluative space, but on how we handle time in the analysis[38]. Valuation processes are beyond the remit of this chapter and it will suffice here to say that the evaluative space needs definition before we consider how to appropriately handle time.

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<sup>4</sup> Arguments of this kind are more common in relation to the use of subjective well-being as a consequent[37].

There are a number of other limitations to the current conception of the health-related QALY that make alternatives worthy of consideration. Some authors have suggested that the concern at end of life may be to provide care rather than health improvement, implying that the receipt of care should be a domain of interest (though providing no justification for this)[31]. It may be more accurate to characterise this as a procedural concern, which is arguably more pertinent to end of life care than to other settings. Similarly, end of life care also raises additional challenges in terms of caring externalities, adaptation and cognition. The extent to which formal frameworks have been developed to address these challenges is limited, and each could be confronted in a variety of ways. Below I discuss some means of addressing these concerns within a health-related QALY approach.

## Reasons to use the health-related QALY in end of life

Having highlighted some shortcomings in the ways in which alternative conceptions of the evaluative space in end of life have been promoted by others, I here defend extra-welfarism as currently defined. I argue that it is important to specify which domains constitute the evaluative space, and that current approaches provide sufficient flexibility and practical tools to allow for the adequate identification of outcomes in end of life care.

### **Context relevance**

In the past, some researchers have shied away from specifying the domains of value to be included in the evaluative space. In doing so they imply that the evaluative space should consist of everything that might determine well-being. This is not untenable in theory, though it is worth noting that the evaluative space would therefore include those aspects of life that some people value but that we might consider to be in some sense 'bad'. However, it is untenable in practice. Proponents of such an approach for the economic evaluation of publicly funded health care have failed to recognise the decision-making context. There is good reason for the current focus on health, as I will explain.

If domains are not specified - even within the consequents of capabilities or functionings - we arrive at a problem also faced within the welfarist approach to cost-effectiveness analysis (i.e. cost-benefit analysis). Objects of value that we might have reason to believe are important - say, provision of a good death - can be traded against all other things that people might value. For example, cosmetic surgery may be deemed more valuable than reconstructive surgery if patients receiving the former have a capability set that is more greatly influenced by their appearance. It also seems probable that providing a patient with the cash value of their health care would increase capabilities and functionings outside the health domain (without restricting capabilities within it), and that publicly funded health care within a National Health Service should necessarily reduce well-being in these terms.

As outlined above, the researcher should not presuppose which objects of value within the evaluative space provide the most information about the value of a given state. Thus, in allowing objects from an unrestricted

domain space, it is possible that health care providers could become responsible for objects of value that in no way relate to either health or health care. It is possible that the identification of the most informationally rich objects within this unrestricted domain space might relate to wealth, freedom, relationship status, employment, intelligence, or any other aspect of life for which health care has no apparent duty or capacity to provide.

Sen suggests that the grounds for offering assistance - for example, in the form of health care - depend on the decision-making context[7]. As Brouwer et al state, "the emphasis in the health care sector is clearly on improving *health*"[4]. It is important to consider this context, and that broadly speaking the health service is neither responsible nor equipped to offer assistance to people in achieving whatever is most valuable to them. Health care is suitably equipped to improve people's health; the health service might be particularly bad - compared to other sectors or services - at supporting individuals' non-health goals. This simply represents a recognition of the contexts in which decisions will be made, rather than an explicit 'decision-making' approach to economic evaluation[40]. Even if decision-makers seek to maximise health in some simplistic fashion, there may still be grounds to argue that economic evaluation in health care should incorporate domains beyond health, notably domains that might be more commonly considered social care.

Introducing a different approach specific to end of life care is not informative to the problem of resource allocation of health care budgets. Sen stated that the norms involved in the specification of the evaluative space must depend on the purpose of the evaluation[7]. Accepting an alternative means of outcome measurement in end of life care forgets this important point. The purpose of economic evaluation in health care is to allocate resources - usually defined by a fixed health care budget - as efficiently and equitably as possible. Those resources allocated to end of life care are the same resources that might alternatively be allocated to other health care, and allocation decisions therefore require evaluation on an equivalent basis.

The context of end of life care, for those whose responsibility it is to allocate health resources, *is* health care. Much of what is considered to be end of life care takes place in hospitals, surgeries and community care settings. It is administered by doctors and nurses. To distinguish end of life care from health care generally would be impossible. The extent to which end of life care is distinguishable from other health care contexts is the same as that for other specific areas (consider the apparent contextual differences between midwifery, psychiatry and emergency care). Existing arguments in favour of separate evaluation of end of life care do not stand to reason where care is funded from a fixed health care budget.

## **Measurability**

Functionings can be measured both objectively and subjectively as necessary and are easy to conceive. Resource based approaches such as Rawls's primary goods are easily observable. Utility is not observable, but

much time and effort has gone into developing methods that are indicative of it. Capabilities are not easily quantified in themselves, and nor is it easy to isolate their value from the value of functionings. As yet, no clear methodology for the successful definition and valuation of capability sets has been developed. As outlined above, the consequent associated with the health-related QALY approach is unclear. My own interpretation is that under certain circumstances preference-based elicitation tools (such as ranking exercises and choice experiments) elicit values associated with both functionings and capabilities. I accept this as the appropriate basis for allocating resources for publicly funded health care.

Central to this is the principle that states should be valued by the general public, rather than by individuals. This means that (most) individuals value hypothetical states in which they have not had cause to select a preferred function set, and thus we might expect respondents to see value in choice<sup>5</sup>. To this extent, appropriate and widely tested methods are available for the purpose of valuing states. There should also be some concern in end of life care about the extent to which individuals have the capacity to either describe or value health states. Most approaches require agency assumptions that might not hold in end of life care, and the role of these assumptions requires further research.

### **Flexibility**

A descriptive system can never be complete, even within narrowly defined domains. Consider an evaluative space defined by the domain of health and the consequent of individual preference satisfaction. Not only will different groups - say, those in end of life care and healthy children - have different preferences, but their health will be differently defined. Any single questionnaire will not provide sufficient information to enable valuation of all objects within the evaluative space for both groups. Within the domain of health, a descriptive system might include any number of items. The goal of the descriptive system is to describe the evaluative space as fully as possible, while maintaining practical value. There is no reason why different descriptive systems - say, for different patient groups - cannot be comparable so long as they both attempt to capture information relating to the same evaluative space<sup>6</sup>. As such, a health-related QALY approach allows for the inclusion - and adequate measurement - of objects of value within the health domain that might only be relevant to specific groups. Interventions for end of life care could be evaluated using a descriptive system that more adequately reflects health concerns at the end of life, and this would be entirely consistent with current approaches.

Neo-classical welfare economics employs strict rules of engagement, namely in demanding utility maximisation, individual sovereignty, consequentialism and welfarism[41]. Extra-welfarism developed by

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<sup>5</sup> The influence of wider choice sets in the hypothetical should be seen as related to but distinct from the influence of uncertainty.

<sup>6</sup> There is practical value in generic instruments that are valid for the majority of patients, but these should not be seen as a panacea.



relaxing these rules to enable such mechanisms as interpersonal comparison, weighting of objects and the sourcing of values from parties other than the individual.

The extra-welfarist framework additionally does not prescribe the inclusion or exclusion of externalities or procedural value and does not insist on specific methods of valuation. It is important that these characteristics are maintained. Caring externalities can (and should) be accounted for insofar as they affect outcomes within the evaluative space; there is no requirement for individual sovereignty. The health-related QALY approach can fully consider caring externalities if these relate to the domain of health. The recent development of the ICECAP Close Person Measure (ICECAP-CPM) demonstrates a process by which such a measure could be developed[42], though the ICECAP-CPM itself extends beyond the domain of health. The inclusion of domains beyond health requires justification, bearing in mind that effects on caring externalities will necessarily be traded against health improvements to the individual. Similarly, the health-related QALY approach could be adapted to account for value in the process and delivery of care[43, 44].

In health care we often observe 'irrational' preferences, and it is important that we adopt a framework that does not enforce strict rules regarding appropriate responses and is inclusive of all views. Furthermore, it is necessary to allow for different forms of data collection from different sources, which can accommodate those with reduced capacity.

While the capability approach has fewer strictures than welfarism, it may be seen to limit the extent to which utility, choice and preference information might be taken into account. A simple dualism of domains and consequents, which I have argued to be based on a self-evident distinction, does not insist on any relationship between consequents or between domains. Such a framework does not require strict causal flows; for example from capabilities to functionings to utility. Therefore, more freedom and clarity is afforded in the definition of a normative position that need not conform to traditional views, and which could employ a variety of valuation techniques and decision rules.

## An agenda for change

In order to adequately capture value in end of life care, and to improve the definition of the evaluative space more generally, I propose the following changes to the health-related QALY approach.

1. Clearer definition by researchers of their own normative position in terms of both consequents and domains.

Much of the debate between different parties in regard to the appropriate evaluation of outcomes in end of life care has been hindered by a lack of clarity. Researchers should clearly lay out their normative position in respect to the domains they deem to be worthy of inclusion in the evaluative space and the consequents that they understand to provide value. Clear definition of the evaluative space needs to be provided prior to the development of descriptive systems that identify specific objects of value, and should guide the selection of

valuation techniques. There is no value in defining differential evaluative spaces for different groups of people when resources are allocated from a single budget, as this precludes efficient and equitable outcomes.

## 2. Appreciation of value beyond consequences to the individual

Having defined the evaluative space in terms of domains and consequents, it is necessary when defining a normative position to also assert to whom improvements are deemed valuable. Particularly within a publicly funded health care system, there seems no reason to limit this to the impact on an individual. Characteristics of people other than the individual recipient of care are valuable. Both positive and negative externalities in terms of the domains and consequents of value should be included within the evaluative space. Likewise, impacts relating to the process rather than the outcome of care should be explicitly acknowledged as being of value.

## 3. Clearer definition of process in the formulation of descriptive systems.

In order to maintain comparability in outcomes across different measures, it is important that descriptive systems provide information on the same evaluative space. In order to achieve this, clear rules need to be established and adhered to for the qualitative and quantitative methods used to identify specific objects of value for inclusion in a descriptive system. The best descriptive system is that which provides the most information about the evaluative space while maintaining practicality in statistical and operational terms.

## 4. Acceptance of a multiplicity of descriptive systems

Much has been made of the comparability or otherwise of different descriptive systems. This is largely due to ambiguity in the definition of the evaluative space. It must be recognised that the role of descriptive systems is not to define the evaluative space but to provide information about it. For any given evaluative space, there should be a great contest to identify descriptive systems and valuation methods that best reflect it. These should be tested in the usual ways in regard to validity and reliability. There should be both generic measures and population-specific measures in order to adequately reflect people's differing priorities. Measures that are condition-specific should not be used if this involves the presupposition that particular disease symptoms are relevant to well-being.

## 5. Recognition of the true nature of valuation processes.

Just as descriptive systems do not define the domains of value, nor do valuation processes define the consequents. Valuation processes in extra-welfarism do not *need* to elicit individual preferences that reflect utility, as utility is expressly not the (only) outcome of value. As such, it is permissible - and here I argue preferable - to use valuation tools that provide information about the extent to which individuals prefer different states for reasons other than their impact on utility. Tools such as visual analogue scales and choice experiments may usefully reflect non-utility information about functionings and capabilities.

## 6. More research into the fundamental dimensions of value

There are some universal dimensions relevant to well-being that transcend any definition of the evaluative space. The most pertinent in end of life care is time. Another is uncertainty. There are arguments that people value time differently at the end of life [38, 45], though this might also apply to other patient groups [46] and as such should not relate exclusively to end of life care. There is a need for more investigation of how people value time and if any differential valuations ought to be considered in economic evaluation. For example, there may be grounds for developing a 3-dimensional QALY in which life years are valued in terms of both quality of life and the value of time.

Each of these suggestions is entirely compatible with extra-welfarism and with the principles of welfare economics more broadly [4].

## Conclusions

Though it seems clear that aspects of life matter 'beyond health' [22, 43], and that people appear to value these items within the context of health care, it does not follow that such items should be included in their own right. Restricting the evaluative space to the domain of health does not mean that only health improvements are achieved, rather it means that we value the extent to which improvements in health can improve well-being more broadly.

The importance of defining the evaluative space has not been adequately recognised by the various approaches to economic evaluation in end of life care, which have focused on the development of descriptive systems and valuation techniques. While current approaches fail on a number of counts, the alternatives appear to fail on the same and perhaps more.

Much has been made of differing normative bases for the arguments, but on inspection it is clear that these arguments lack focus; confusing the domains and consequents of the preferred evaluative space. I hope this chapter might assist in the debate between those who support and those who oppose current approaches, and enable each to detail with clarity any points of departure.

The end of life is unique; people only experience it once. But there are many things in life that people only experience once, and this is no grounds for special treatment. As currently described and operationalised, alternative outcome measures such as the ICECAP-SCM should not inform the allocation of resources in health care because they are based on an alternative evaluative space and lack context relevance. However, in practice we might expect such measures to converge with existing 'preference-based' approaches due to ambiguity and imprecision in both. The development of a clear and consistent approach to the evaluation of end of life care within the health care context is needed. The alternative is to risk inefficient and inequitable allocations of resources.

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