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PATIENT CENTRED OUTCOME MEASUREMENT IN HEALTH ECONOMICS: BEYOND EQ-5D AND THE QALY – WHERE ARE WE NOW?

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Decisions about choice of outcome measures outside of the economics context tend to focus on a two-way conflict between (i) the ideal form of measurement in any specific context and (ii) what is practically feasible. But for measurement for economic purposes, there are two additional, related, conflicts: (iii) what is required of the measure for it to be consistent with economic theory/the economic decision-making context, and (iv) what value judgements are acceptable within this theoretical approach.

The purpose of outcome measurement for economics is its use in economic evaluation to enable decision-makers to weigh up costs and benefits of alternative courses of action: relatively simple decisions such as whether to spend on medication or cognitive approaches to relieve pain for palliative care patients; or more complex decisions such as whether to spend more on pain relief for palliative care patients, or more on constipation management for this same group of patients, or more on providing cochlear implants for those with hearing loss, or more on providing social care for those with learning disability. Economists talk in terms of technical efficiency (achieving a specific outcome at least cost) or allocative efficiency (achieving a pattern of spending that provides those services most valued by society). Outcome measurement for technical efficiency questions is relatively simple: it often mirrors the outcome measurement required for randomised controlled trials and, in the first example above, could focus on pain. Combined with cost information, analysis can then determine the most efficient alternative. As soon as decisions move in the direction of allocative efficiency, however, everything becomes much more complex; it is at this point that the Quality-Adjusted Life-Year, or QALY, enters the equation.

The QALY is a means of trying to combine quality and length of life into a single outcome that can be used in all conditions, thus enabling comparability across all interventions on the fundamental issue that is perceived as important to health decision-makers: gains in health (1, 2). Value judgements explicitly or implicitly include that:

- generic health functioning (what a person actually does/is in terms of their health only) is the appropriate evaluative space (rather than, for example, broader notions such as capability wellbeing (what a person is able to achieve in life more broadly));
- the person is the best judge of their own health state;
- the population is the best judge of the value of that health state;

- ‘perfect health’ has a value of one, the state of ‘being dead’ a value of zero, and that values in-between (and indeed below zero), can be used to represent various health states according to population preferences;
- the values of intermediate states are judged by the ‘average’ individual’s willingness to trade-off quality of life in that state against time in that state or by alternative methods such as the ‘average’ individual’s willingness to trade between a certain health state and the risk of dying;
- time in a state can be multiplied by the value for the quality of life in that state;
- the purpose of the health system is to maximise health gain across the population.

Generic health measures with associated population value sets (or ‘tariffs’) are commonly preferred to condition-specific measures, as they provide comparability across interventions. A key measure recommended by decision-makers in a number of countries is the EuroQol EQ-5D, which comprises a quality of life measure with five dimensions: *Mobility; Self-care; Usual activities; Pain/discomfort; and Anxiety/depression*. There are two versions; ‘EQ-5D’ is used here as a shorthand to include both three level (EQ-5D-3L) (3) and five level (EQ-5D-5L) (4, 5) versions.

Although some support using a QALY approach to evaluate palliative and end of life interventions (6), there is also concern in this context about the appropriateness of basing decisions upon economic evaluations using QALYs (7-9), with a recent integrative review identifying three challenges (10). Conceptually, these focused on two of the value judgements outlined above: concerns about the adequacy of the evaluative space, and concerns about the additivity of time. A third challenge related to a more practical implication of using QALYs, in that the low levels of remaining life expectancy inevitably restrict potential QALY gains (10) (potentially perceived as unfair). There was little discussion of appropriate methods for generating tariffs or of appropriate populations from whom to generate these tariffs, perhaps reflecting that the few attempts to go ‘beyond’ the generic health QALY in this context have so far focused primarily on the nature of the evaluative space, rather than its valuation.

Nevertheless, moving beyond generic health measures such as EQ-5D to form QALYs, is an active area of investigation in evaluation of palliative and end of life care, with research moving in two directions, employing differing value judgements. The first remains within the general QALY paradigm whilst relaxing the value judgement around use of generic

health measures, in favour of using a 'health' measure that reflects health issues faced by those receiving palliative care (11). The second is more radical, questioning more of the value judgements associated with QALY maximisation (9) and shifting focus towards capability wellbeing amongst those at end of life (12-14) and persons close to them (15). These approaches mirror those outside of the palliative/end of life context.

The first tranche of research builds on an existing, widely used measure, the Palliative care Outcomes Scale (POS) and its forerunner, the Support Team Assessment Schedule(16), to develop a new scale, the POS-E. POS-E has been derived from the existing ten-item, five level POS (11). This is a point at which practical considerations enter: the POS scale itself is too large to feasibly produce a full value set, and so a derived seven-item scale has been generated, with each item having smaller numbers (two or three) of levels (11). Dimensions of POS-E are: *Pain; Other symptoms; Depression; Anxiety; Family anxiety; Feeling good; and Practical matters.*

There are further challenges for the POS-E before it can be fully used in economic evaluation. As yet, there are no published values, and the validity of the shortened version needs testing. Assuming that valuation methods conform to the usual assumption of valuing death at zero, using POS-E for decision making within palliative care (technical efficiency) may be relatively uncontroversial. Even if it were used just in this context, however, the question of whether existing cost-effectiveness thresholds are appropriate would need to be addressed. For use in allocative decisions, it is likely that mapping to existing generic measures would be required.

The second tranche of work builds on a broader research programme (ICECAP) to design capability wellbeing measures for use in economic evaluation across the life-course. The seven items within the ICECAP Supportive Care Measure (ICECAP-SCM) were generated through in-depth interviews with individuals at different points along the trajectory towards death. They comprise: *Choice; Love and affection; freedom from Physical suffering; freedom from Emotional suffering; Dignity; Support; and Preparation* (12). Both pilot (17) and full (14) valuation exercises with members of the public, using a technique known as best-worst scaling (14,17,18), have recently been published; values are generated between full capability and no capability, and death is assumed to be a state of no capability (18). The measure is feasible for use with hospice patients (13) and a companion close person measure (ICECAP-CPM) has been published (15). More generally, research has considered alternative

approaches to decision-making, assuming that the focus of decision making is on those not yet achieving a 'sufficient' level of capability (19).

As with POS-E, there are challenges still to be addressed in using ICECAP-SCM in decision making and, given the scale of ambition in moving into a broader capability wellbeing paradigm, these are probably greater. For ICECAP-SCM there are, as yet, no large validity studies of the use of the measure although the measure is incorporated into a number of ongoing studies. Values are generated from the general population, but values from those at end of life might be more appropriate. More generally, there are issues around what an appropriate monetary threshold would be for capability measures (the focus of a current research study using deliberative methods (20)) and how to shift between measures as a person moves through the life-course.

To conclude, we return to the dual themes of conflict and compromise introduced in the opening paragraph. A shift in focus within the economic paradigm is not as simple as choosing one measure over another; it also requires engagement with relevant economic theory, the extensive value judgements incorporated into any approach, and the subsequent decision making process. Using EQ-5D within the QALY paradigm incorporates a value judgement about what is important to patients at end of life that many professionals working within palliative care find unacceptable. Alternatives are on the horizon, but these require further work and exploration, although including either one or other of these measures alongside EQ-5D in as many studies as possible will add to existing evidence, and 'future-proof' studies as these alternatives become more extensively used. Just as important, there is an urgent need for new research within health economics to address other fundamental aspects of valuation, particularly in relation to the issues around the additivity of time discussed by Normand (8) and highlighted by Wichmann et al (10). Such research can also be expected to introduce further conflict and generate new compromises.

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