



# Independence in Dependence

## Health Technology Assessment, Quality



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Health Technology Assessment, Quality of Life, and the  
Position of the Patient

Matthias Benzer

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# Independence in Dependence

## Health Technology Assessment, Quality of Life, and the Position of the Patient\*

Matthias Benzer\*\*

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### Abstract

This paper presents an examination of the UK National Institute for Health and Clinical Excellence's (NICE) proposed procedure for cost-effectiveness assessments which are meant to inform recommendations for decisions on which health technologies the National Health Service should fund. The focus rests on the situation this framework constructs for the patient. The enquiry is oriented by extant studies that suggest that quality of life (QOL) frameworks employed in contemporary healthcare settings articulate the problem of independence and dependence and that they thus echo socially prevalent modes of thinking personhood. The position NICE's framework constructs for the patient can be elucidated with a view to the problems of independence and dependence. NICE's procedure supports the notion that patients should be actively involved in describing their health and by dint of the Institute's preferred QOL description tool, the EQ-5D, reflects a positive appreciation of a specific form of independence and self-sufficiency for the patient. By virtue of enlisting the general public in QOL valuation, NICE's approach assigns the public the position of consumers and constructs for patients a situation of passivity and a relationship of dependence on the public's health preferences. The question about the position envisioned for patients in the health sector can be posed anew.

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correct knowledge of HIV issues' as well as 'medication, counselling and care' – on being given expert help, health products, and services (2008: 1574).

The following enquiry is oriented by these studies consistent with Rapley's suggestion to read 'ideas' such as QOL in respect of the 'commit[ments]' to specific 'social realities' they reflect (2003: 125) and with a view to underlying 'cultural, political' modes of 'understanding.. the nature of personhood' (2003: 128). The focus of the examination rests on the National Institute for Health and Clinical Excellence (NICE) proposed mode of procedure for cost-effectiveness assessments of health technologies. Such assessments are to inform recommendations for decisions on which health technologies the National Health Service should fund for patients. According to Speight and Rea (2009) '[h]ealth technology assessments, performed by organisations such as NICE ..., can make or break a drug – and, consequently, make or break the lives of many people who may benefit from that drug. Indeed, NICE's approach and the quality-adjusted life year procedure that operates within it have fomented well-born moral philosophical debates (see e.g. Claxton and Culyer 2006; Harris 1987; 1995; 2005a; 2005b; Hope 1996; Rawlins and Dillon 2005; Quigley 2007; Schlander 2008). Rather than pursuing these debates however, the following considerations concentrate on the situation that NICE's framework constructs for the patient. This construction can be cast into sharp relief precisely with a view to issues such as independence and dependence. NICE's framework raises these issues in its own specific manner whilst in some ways also resembling QOL frameworks analysed in previous studies. It thus poses renewed questions about the position ascribed to patients in contemporary health systems

NICE's cost-effectiveness analytical approach

The National Institute for Health and Clinical Excellence issues

guidance on promoting good health and preventing and treating illness in England and Wales. It was established in 1999 to offer National Health Service (NHS) professional advice on how to provide their patients with the highest attainable standards of care and to reduce variation in the quality of care (Littlejohns 2009: 1).

One mainstream of NICE's work consists of health technology appraisals (HTAs)<sup>3</sup> NICE produces 'guidance to the NHS on the use of drugs, medical devices, diagnostic techniques, surgical procedures etc. (Amis 2009: 29). HTAs involve recommending which treatments the NHS should fund. The recommendations rest on enquiries into many aspects of technologies (NICE 2008a). Crucially for NICE, 'limited healthcare resources' (2008b 9) and 'rapid advances in modern medicine' render the NHS unable to invest in every

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<sup>3</sup> Schlander (2007) offers a case study

technically available treatment that promises beneficial effects (2010a). A key function of HTAs is checking whether technologies are cost-effective – provide value for money<sup>4</sup> – before they are recommended for NHS funding (2008b: 17–18; Tosh et al. 2011: 103). Indeed NICE is often considered a ‘role model for the implementation of cost-effectiveness analysis, as an integral part of health technology assessments to support informed decisions about the rational allocation of health care resources in an environment of economic limitations’ (Schlander 2007: 3–5). The Institute’s foundation has been described as ‘a clear indication of the extent to which the language and tools of economic expertise now pervade the regulation of healthcare’ (Kraak and Miller 2008: 17)

NICE’s (2008a) guidelines for technology appraisal are ‘not completely prescriptive’

2009; NICE 2008a: 38; Tosh et al. 2011: 103–4; see also Brazier 2007). NICE prefers a representative sample of the UK public, professionals or patients themselves to value the health state in respect of those QOL features that patients using the EQ-5D have attributed to it – and assign utilities or QOL weights between negative values and 1 (Dolan et al. 2009; NICE 2008a: 38; Tosh et al. 2011: 104; see also Brazier 2007).

NICE (2010a) exemplifies its cost-effectiveness analytical approach with reference to a patient in a life-threatening condition. At £3,000, current treatment puts her in a health state with a 0.4 QOL weight for 1 year, yielding 0.4 QALYs. At £10,000, the new treatment puts her in a state with a 0.6 QOL weight for 1.25 years, yielding 0.75 QALYs. The new technology yields 0.35 extra QALYs for £7,000, costing £20,000/QALY gained.

The Institute emphasises that whilst ‘consideration of the cost effectiveness of a technology is a necessary basis for decision-making’ (2008a: 58), it also ‘takes into account other specified considerations when issuing guidance to the NHS’ (2008a: 9; see also 2008b: 17–18). NICE, that is, has no particular £/QALY threshold above which technologies are automatically rejected (Devlin and Parkin 2004; Littlejohns and Rawlins 2009: 116; NICE 2008b: 18; Pearson and Rawlins 2005: 2619; Rawlins and Culyer 2004). Still, the ‘estimates of clinical and cost effectiveness are, individually, key inputs into the decision-making of the Appraisal Committee’ (NICE 2008a: 27). NICE usually considers treatments costing over £20,000–30,000 per extra QALY not cost-effective (2010a; see also 2008b: 18; Walker et al. 2007: 56). Above... £30,000 per QALY gained, advisory bodies will need to make an increasingly stronger case supporting the intervention as an effective use of NHS resources’ (NICE 2008b: 19; see also 2008a: 59).

Independence..

In NICE’s method for cost-effectiveness assessment of health technologies, the first step towards determining QOL weights for QALY calculations involves asking patients to describe their health’s QOL characteristics by means of the EQ-5D Questionnaire. The EQ-5D is NICE’s ‘preferred’ device, not the only instrument it ever permits (2008a: 38–9; see also Brazier 2007: 9; Kelson et al. 2009). What Tosh et al. (2011: 104–5), reviewing NICE HTAs between 2004–2008, found is that it was employed more in evidence submissions than any other tool and that NICE’s current guide to HTA methods gives even ‘stronger encouragement for the use of EQ-5D’ than the previous version.



NICE's procedure echoes HRQoL [health-related quality of life] philosophy in that

respondent thus selects a five-digit code to describe her HRQOL<sup>14</sup> (Rabin et al. 2011; see also Brazier et al. 2007: 29–31, 195–200; Dolan et al. 2009; Rabin and de Charro 2001; Rabin et al. 2004).

The EQ5D's orientation is normative. Mobility, self-care, and usual activities are considered desirable, contributing to a good life quality, pain/discomfort and anxiety/depression undesirable. More precisely, what is desirable is each domain's severity level 1 – conceived as the desirable, not necessarily authentic, manifestation of that domain; level 3 is conceived as the undesirable manifestation; level 2 is situated somewhere in between.<sup>15</sup> The following discussion focuses on the first three dimensions, as is through the notion of life reflected by its normative claims that having no problems in mobility, self-care, and usual activities benefits QOL. The questionnaire begins to delineate the patient's situation in respect of her independence and dependence.

### Mobility and self-care

Unlike what the term may imply, 'Mobility', the first EQ-5D QOL dimension (Rabin et al. 2011: 5), does not include the 'ability to move or... be moved' or 'capacity for movement or change of place' generally (OED 2012, s.v. 'mobility'). The 'use of bicycle, car or public transport' for instance, is excluded. EuroQol mobility means 'physical ability to walk or move about... inside and outside' (Brook et al. 2003: 283).<sup>16</sup> The questionnaire formulates severity level 1 as 'have no problems in walking about' (Rabin et al. 2011: 5). This category however, does not include everyone with no trouble walking about, but only those without problems in walking about independently without any aids. The EQ5D does not make this explicit, but according to the EuroQol Group's official specifications of its concepts – 'should not be given to respondents' (Fox-Rushby and Selai 2003: 172) – walking about means 'ability to walk or move about independently from one place to another, both inside and outside'. Level 1 'could be interpreted as: Can walk (about) without help or aids' (Brook et al. 2003: 283–4). In 1996, a questionnaire was sent to 23 EuroQol Group members 'who had been involved during the development of the Instrument... Each person was asked to write about what they thought the Group meant

<sup>14</sup> 22112, for instance, means some problems in walking about, some problems washing or dressing herself, and moderate anxiety or depression (level 2 respectively) experienced by the patient in the mobility, self and anxiety/depression dimensions, but no problems with performing her usual activities and no pain or discomfort (1) experienced in usual activities and pain/discomfort (Rabin et al. 2011).

<sup>15</sup> The 'dimensions... constitute ordinal scales in which level  $i+1$  is 'worse than' level  $i$ , '<' meaning 'worse than' (Dolan and Kind 2005: 141), not necessarily less authentic than'. But 'the numerals 31 have no arithmetic properties and should not be used as a cardinal score' (Rabin et al. 2011: 4).

<sup>16</sup> Some EuroQol members have questioned this official definition, proposing that 'mobility' should mean 'ability to move from one place to another and includ[e] walking, moving in a wheelchair, and driving/transport' (Fox-Rushby and Selai 2003: 170).

<sup>17</sup> The definitions 'may ... contribute to an explanatory background for EQ application studies', but are mainly aimed at 'researchers and translators of the EQ to help in the choice of the most appropriate words in another language' (Fox-Rushby and Selai 2003: 172). Problems of translation, which has long been a major issue for the Group (Fox-Rushby and Badia 1995; Fox-Rushby and Selai 2003; Rabin et al. 2003), 'led the Group to consider more closely the meanings of concepts and the related wording used in EQs and de Charro 2003: 236). The tool is presently available in over 100 languages (EuroQol Group 2012).

to convey by a set of words or phrases' (Rushby 2005: 36–7) in an attempt to draw out the intended meanings of the survey questions by the original developer<sup>18</sup> (Fox-Rushby and Selai 2003: 168). The response 'walking about' revealed that '[i]ndependence in walking appeared to be a highly valued state by the EuroQol Group' (Fox-Rushby 2005: 40).

Indeed the instrument's initial, six-dimensional version formulated severity level 2 as: 'Unable to walk about without a stick, crutch or walking frame' (EuroQol Group 1990: 204). Level 2 was not simply supposed to capture those unable to walk about (and not classed as level 3), but included those who have no problems in walking about in walking about without any problems, depend on a stick, crutch, or walking frame. For the current version, level 2 was reformulated as 'have some problems in walking about' (Rabin et al. 2011: 5) 'so as to not exclude people who use other types of walking aid, or people who had problems walking but did not use an aid' (Gudex 2005: 23). According to this rationale, severity level 2 for mobility appears to include not only those with some problems in walking about (and not classed as level 3), but also those who have no problems in walking about but, in walking about without any problems, depend on some type of aid. Officially, 'Level 2' means '[n]eed to use stick, crutches, walking frame, when walking' and '[w]ould include people in a wheelchair although they may not classify themselves in level 2' (Brooks et al. 2003: 284) 'have no problems in walking about' reserved for those with no problems in walking about independently without any aids.

Throughout the EQ5D treats level 1 of each dimension as a contribution to good QOL, as the respective dimension's desirable albeit not necessarily authentic – manifestation. The normative claim here is that a desirable level of mobility, i.e. walking about, cannot be reached by everyone who has no problems walking about. The quality of life of those who have no trouble walking about but thereby depend on aids inevitably offers trouble free walking about which is independent, free of all help and aids, accomplished solely by the individual's own body<sup>19</sup> constitutes a desirable mode of mobility conducive to a good quality life. The EQ5D expresses a positive evaluation of mobility and walking about which is closely intertwined with a particular notion of independence and self-sufficiency.

The questionnaire formulates the undesirable mobility level 3 as 'I am confined to bed' (Rabin et al. 2011: 5) it is officially specified as '[r]estricted to staying in bed (except to use the toilet)' and 'includes being confined to a chair (but not wheelchair) all day (e.g. where someone is moved from bed to a chair and returned to bed at the end of the day' (Brooks et al. 2003: 283). Fox-Rushby (2005: 40) summarises the responses on this category's meaning from EuroQol Group members who completed the aforementioned survey

<sup>18</sup> This exercise, too, was meant to aid translation (Rushby and Selai 2003: 168).

<sup>19</sup> See also Fox-Rushby and Selai (2003: 70) and Rabin et al. (2003: 193)



any problems in ensuring that her self is cared for, depends on others in ensuring care for her self without any problems. Only a person without any trouble in caring for her self herself, independently of others, reaches level 1.

According to level 0.332(s)-13(5i)-oD level 0.332(s)-13(c) on a 66 0 T ( on (6 0 -4(.))TJ Tc 0 Tw 2J level -35 or on caJ 0 1w 2pef1-op 0 Tw 2.96 0 ur16( t0 16ohi)-op 0 Tw 2.96 0 urf1-o Tdeoif level (bi) Twi 26 w steve 3.93 0 0 500 level 0.332(s)-13(ca)-2(s) 1.90 Tj T (W)-6(ev)-14(el)-6

The EQ5D's treatment of mobility and self-care, conveying as it does a positive appreciation of independence from aids and help from others, certainly raises the problem of independence and dependence in

image of the 'individualistic rather than.. dependent' subject is accepted across much of today's





enterprising subject, Rose also highlights the 'prevailing image of the worker' as 'an individual in search of... fulfilment' (1992: 154) and of 'work' as both a way of 'fulfil[ling] ourselves' (1992: 151) and a realm in which productivity is to be enhanced ... through the active engagement of the [employee's] fulfilling impulses' (1992: 154).<sup>22</sup> Contextualising the QOL ideas employed in the governance of Britain's intellectual disability services in the 1990s, Rapley refers to the Department of Health's assertion that people with learning disabilities could similarly benefit from remunerated employment: '[t]he



possible health – with 0 assigned to (equivalence with) being dead<sup>24</sup> (Brazier et al. 2005: 201; Dolan et al. 1996; 2009; NICE 2008–9; 2010) see also Brazier et al. 2007

The public as consumer

A QOL weight stands for a subjective evaluation of a health state in respect to the patient's QOL properties experienced by her and articulated through EQD. More precisely the weight represents an evaluation of that health state by a subject imagining herself to be this patient (Brazier et al. 2005: 201; Devlin and Parkin 2007: 44; Dolan et al. 2009; Nord et al. 2005: 125). Numerical QOL weights reflect the sizes of the 'values that people... hold ... about what it is like to be in various health states' (EuroQol Group 1990: 205; see also Devlin and Parkin 2007: 44) Quality weights are also called 'health-related utility values' (NICE 2008a: 39; see also Brazier 2007) or 'preference weights' (Rapley 2003: 145). 'In health economics, a "utility" is the measure of the preference or value that an individual or society places upon a particular health state' (NICE 2011; see also 2008a: 76; Brazier et al. 2007: 331, 334; Walker et al. 2007: 55; Weinstein et al. 2009: S5). The numerical QOL weight is meant to represent the extent of subjective preference, and the degree of subjective satisfaction the evaluating subject expects to derive from being in, a health state in which patients have and experience a specific combination of five QOL properties represented by the EQD.<sup>25</sup>

Citing 'evidence of significant discrepancies in health state values by illness experience', Brazier et al. (2005: 202) note that choosing between the public and patients' weights greatly affects estimates of treatments' health gain, 'incremental cost effectiveness ratios', and 'funding decisions'. By resolving to ask the public to ascribe numerical QOL weights to health states based on their subjective preferences, NICE –



57, see also 14 1989: 227; 1992; Heelas and Morris 1992: 178) revision of members of the public in the position of consumers, in turn, renders the construction of the position for the patient more multifaceted than it might have appeared so far

#### Position of dependence

To prevent misunderstanding, Kelson et al. (2009; cf. Speight and Reaney 2009) legitimate rejection of the claim that NICE does not consider patients' views highlighting. NICE's motto of 'inclusiveness' means that its guidance development should involve patients and patient carer organisations alongside other interested parties (2008b: 13). The Institute is committed to – and supported by its Patient and Public Involvement Programme – engaging patients (Amis 2009; Kelson 2009: 10–11; NICE 2004a; 2007: 18–19, 36)

Nor are patients' contributions to NICE technology appraisals reduced to ticking EQ5D boxes (Amis 2009: 30; NICE 2004a: 8; Quennell 2001: 212) and patient organisations are among those NICE asks to provide feedback on the appraisal's draft scope and provisional matrix to help finalise items a definition of questions, technologies, clinical problems, patient groups, outcomes etc. and of stakeholders invited to participate in the appraisal (Amis 2009: 31–2; Kelson et al. 2009; NICE 2004a: 11–13, 35; 2008a: 8–13; 2009: 21–16; Quennell 2001: 212; Schlander 2007: 29–30; Walker et al. 2007: 58). Patient organisations are also encouraged to intervene in the appraisal process itself, especially as consultees (Amis 2009: 31; Kelson et al. 2009; NICE 2009: 13; Schlander 2007: 35). Gatekeeper organisations have the opportunity to submit written evidence – including patients' views on the consequences of a condition and a technology for their lives and what the key outcomes are – which the appraisal committee will review when developing recommendations (Amis 2009: 32–3; NICE 2004a: 6, 16, 29–33; 2008a: 22–3; 2009: 18–19; Quennell 2001: 212; Walker et al. 2007: 62) Moreover, the committee considers participating patient organisations'



For NICE, choosing whose preferences to use for valuation of health outcomes' constitutes 'essentially' a 'value judgement' (2008a: 31; see also Brazier 2007: 170). Now, NICE's mode of procedure for cost-effectiveness assessment of health technologies reflects a normative conception of the patient's life already by virtue of its first step towards determining QO

independent living is simultaneously consistent with the notion of members of the public as autonomous healthcare consumers – which in turn lends support to the construction of the patient's dependence on public preferences.

In constructing the patient's dependence on public preferences, NICE's work conceptualises a very specific dependency relationship. Nevertheless, it is relevant to point out that some of the QOL frameworks scrutinised by scholars, too, inscribe individuals into dependencies, albeit in quite different ways. As noted outset, the discourse Finn and Sarangi have analysed both singles out self-sufficiency as a prerequisite for QOL and depicts the successful pursuit of QOL as dependent on receiving expert assistance, healthcare products, and services (2008: 153-5). Early, the functionality discourse Katz and Marshall have deciphered with a view to the objective of independence it reflects (2004: 58,



corresponds with the replacement of the themes of collective provision and social

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