



Independence in Dependence

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

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Matthias Benzer

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Independence in Dependence

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

Matthias Benzer**

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 to 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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Introduction

In present-day Western health sciences and systems, quality of life (QOL) frameworks are among the most common devices for conceptualising human life and for guiding decisions on intervening in it. As early as 1987, it had reportedly ‘become fashionable to equate health, defined comprehensively, with *quality of life*’ – though concepts of health are still generally narrower (Ware 1987: 474). Simultaneously, QOL conceptions ‘remain[n] ... controversial ... not least because of non-consensus over meaning and measurement’ (Finn and Sarangi 2008: 1568). Applications of QOL frameworks in the health sector have nonetheless received little critical attention from social scientists.

What some of the studies that have been conducted suggest is that conceptions of life quality in healthcare contexts raise the issue of independence and dependence, and that this problem has deeply political resonances¹ (Finn and Sarangi 2008; Katz and Marshall 2004; Rapley 2003; Rapley and Ridgway 1998; Reuter 2007). Finn and Sarangi (2008), for example, analyse QOL conceptions of NGOs involved in India’s HIV/AIDS management. They read these conceptions neither simply as depictions of life nor as instruments for its direct coercion, but, following Foucault, in connection with delicate techniques through which individuals are persuaded to administer and conduct themselves according to certain normative standards in pursuit of quality lives (Finn and Sarangi 2008: 1569–71). A key dimension of Indian HIV-NGOs’ conceptions of life quality is the notion that it ‘require[s] ... responsible self-motivation’ and ‘self-sufficiency’ and conflicts with ‘laziness’ and ‘relying on welfare’. Such ‘principles of QOL’, Finn and Sarangi argue, ‘clearly resonate with the neoliberal configuration of the self-providing, independent ... subject’ (2008: 1575). Simultaneously, their study indicates that the same QOL discourse legitimates forms of dependency:² the successful pursuit of QOL is said to depend on receiving ‘full and

¹ That social approaches to the physical existence of humans raise the problem of independence and dependence with wider political resonances has been known for much longer, of course. In 1983, Michel Foucault famously (see e.g. McNay 1994: 128–9) argued that the French social security system, more and more protective of people such as those in ill health, ‘has ... had “perverse effects”’: individuals ‘are being made increasingly dependent’ amidst ever louder calls for greater independence from social institutions (Foucault 1988: 160–1). ‘Ought we not’, he asked, ‘... to think out a ... system of social coverage that takes into account this demand for autonomy, so that these effects of dependence will disappear almost entirely?’ (1988: 162) To Foucault, ‘[t]he aim of optimal social security combined with maximum independence’ was ‘clear enough’ (1988: 165). Twenty years earlier, Theodor Adorno, criticising West Germany’s sexual offences legislation and best loved sexual taboos, had alleged that the ‘constitution of contemporary life’ was ailing from a massive ‘disproportion between the overpowering institutions and the minuscule scope of action granted [the individual]’. Yet at the same time people were increasingly ‘burdened with ... autonomy’ (Adorno 1998: 77). The ‘members of contemporary masses’, Adorno had argued in an earlier paper, ‘are ... the children of a liberal, competitive and individualistic society, and conditioned to maintain themselves as independent, self-sustaining units’ (2003: 412). Individuals, he now emphasised, were ‘feel[ing] overtaxed and threatened’ (1998: 77).

² This is not to downplay Finn and Sarangi’s pressing critique of the ‘talk of a responsible and self-sufficient QOL ... as meaningless’ vis-à-vis the reality of many lives: due to ‘rejection’, ‘discrimination’, and a lack of ‘skills’, HIV-positive Indian women, for instance, have trouble even surviving independently (2008: 1576).

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: 123). The focus of the examination rests on the National Institute for Health and Clinical Excellence’s (NICE) proposed mode of procedure for cost-effectiveness assessments of health technologies. Such assessments are to inform recommendations for thorny decisions on which health technologies the National Health Service should fund for patients. According to Speight and Reaney (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-known 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 sharper 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 ill health in England and Wales. It was established ... in 1999 to offer National Health Service (NHS) professionals 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 main stream of NICE’s work consists of health technology appraisals (HTAs).³ 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

³ 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’⁴ – 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’ (Kurunmäki and Miller 2008: 17).

NICE’s (2008a) guidelines for technology appraisal, albeit ‘not completely prescriptive’, outline a ‘reference case economic evaluation’ (Griffin et al. 2008: 137–8). The ‘reference case’ presents the ‘methods’ for cost-effectiveness analyses of health technologies that NICE deems ‘most appropriate for the Appraisal Committee’s purpose and consistent with an NHS objective of maximising health gain from limited resources’ (2008a: 31; see also Schlander 2007: 31; Walker et al. 2007: 54). It aims to guide ‘those conducting and submitting cost-effectiveness evaluations to the NICE Technology Appraisals program and to promote consistency in the methods used between submissions’ (Tosh et al. 2011: 107–8).

NICE’s approach is widely known (e.g. Dolan et al. 2009; Griffin et al. 2008; Tosh et al. 2011; Walker et al. 2007; see also Brazier et al. 2007; Weinstein et al. 2009). Its succinct expression of cost-effectiveness is ‘£ per QALY’: following its reference case, NICE calculates how many extra ‘quality-adjusted life years’ per unit of health expenditure a treatment yields⁵ (2010a; see also 2008a: 33; 2008b: 17–19). The required QALY results for health with and without treatment are computed by ‘weighting’ – i.e. multiplying – ‘the time spent in a health state by a value placed on the quality of life ... associated with that health state’ (Tosh et al. 2011: 103; see also Dolan et al. 2009; NICE 2008a: 14, 38; 2010a). Length of lifetime is expressed as number of years of life in a health state. The QOL valuation is expressed as this state’s QOL weight on a scale where 0 is given to being dead, 1 to full health, and negative values to states deemed worse than dead (Dolan et al. 2009; NICE 2010a; Tosh et al. 2011: 103).

Determining QOL weights for QALY calculations involves two steps. First, *patients describe* their health’s QOL characteristics (occasionally carers provide data, but not health professionals). NICE’s favoured description tool is the EQ-5D questionnaire⁶ (Dolan et al.

⁴ ‘Cost effectiveness: value for money; a ... treatment is said to be “cost effective” if it gives a greater health gain than could be achieved by using the resources in other ways’ (NICE 2008b: 4n2).

⁵ ‘The QALY was originally developed as a measure of health effectiveness for cost-effectiveness analysis, a method intended to aid decision-makers charged with allocating scarce resources across competing health-care programs’ (Weinstein et al. 2009: S5).

⁶ The device was ‘expressly developed for application in ... economic analysis’, such as ‘cost-effectiveness’ and ‘cost-utility’ assessments (Krabbe and Weijnen 2003: 8), and ‘intended to be a generic measure with interval properties that allows the calculation of QALYs’ (Brooks and EuroQol Group 1996: 57).

2009; NICE 2008a: 38; Tosh et al. 2011: 103–4; see also Brazier 2007). Second, NICE prefers a representative sample of the UK *public* to 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 rejected⁷ (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).⁸ 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 for supporting the intervention as an effective use of NHS resources ...’ (NICE 2008b: 19; see also 2008a: 59).⁹

Independence ...

In NICE’s method for cost-effectiveness assessments 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 in more 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.

⁷ On this contested issue, see work cited in this paragraph and McCabe et al. (2008).

⁸ Speight and Reaney (2009) consider ‘[c]ost effectiveness ... arguably the most influential factor in the provision of health care in the 21st century’.

⁹ ‘As the incremental cost effectiveness ratio increases, the likelihood of rejection on grounds of cost ineffectiveness rises’ (Rawlins and Culyer 2004).

NICE's procedure echoes 'HRQoL [health-related quality of life] philosophy' in that 'HRQoL philosophy is a move away from the view that the expert knows best' (Selai and Rosser 2005: 103). The patient – not the expert or professional assisting the patient with a classification device – has the best potential, and is given the responsibility, to observe and describe her HRQoL.¹⁰ NICE's idea of the patient's role is reminiscent of what some see as a wider trend in the governance of contemporary healthcare. Rapley (2003: 139), for instance, quotes the UK Health Department's 2001 proposal that exploring the “untapped resource” that is the patient's “knowledge and experience” of her own ill health “could greatly benefit the quality of patients' care and ... their quality of life”. Rapley (2003: 139) seems to consider this suggestion resonant with, but not yet fully elucidated by, 'Rose's (1992) conception of the rights and duties of “entrepreneurial selves” in postmodernity' and 'the increasing responsibility of persons to collaborate with the professions in the use of technologies of the self'. However, what Rose and Miller (2010: 293) emphasise is that since the 1970s the healthcare user has been 'transformed ... from a passive patient ... to a person who ... was ... to voice his or her experiences in the consulting room' and 'exercise a continual informed scrutiny of the health consequences of diet, lifestyle and work'. This transformation, they write, has partaken in the development of a “neo-liberal” mode of government of health' (2010: 293). In fact, in several 'ethical regimes' this “responsibilization” of the self', encouraging an expert-guided 'reflexive hermeneutics that will afford self-knowledge and self-mastery', has become a dominant '*a priori*' (Rose 1992: 149). In advanced liberal democracies more generally, people should 'become “experts of themselves”' and 'adopt [a] ... knowledgeable relation of self-care in respect of their bodies, their minds, their forms of conduct ...' (Rose 1996: 59).

EQ-5D

Given its major function at the heart of NICE's cost-effectiveness assessment approach, the EQ-5D, developed in the late 1980s by the EuroQol Group,¹¹ invites closer scrutiny. The EQ-5D names five quality of life dimensions: mobility, self-care, usual activities, pain/discomfort, anxiety/depression.¹² In each corresponding section of the questionnaire, patients are asked to tick one of three statements coded 1, 2, and 3 to classify their HRQoL, e.g. 'I am not anxious or depressed' (1), or '... moderately anxious ...' (2), or '... extremely ...' (3), in 'Anxiety/Depression'. Each section's coded statements express three distinct severity levels – no problems (level 1), some/moderate problems (2), extreme problems/unable (3) experienced by the patient – in the respective domain.¹³ The

¹⁰ The EQ-5D's developers were from the outset 'anxious that HRQoL be measured ... by people themselves' (Brooks 2003: 2; see also Brooks et al. 2003: 271, 275, 283; EuroQol Group 1990: 202).

¹¹ For remarks on the tool's developmental history, which cannot be traced here, see Brooks (2003); Brooks and de Charro (2003); Brooks and EuroQol Group (1996); EuroQol Group (1990); Gudex (2005); Rabin and de Charro (2001); Williams (2003; 2005a; 2005b).

¹² These are not considered all there is to HRQoL (Gudex 2005: 19–21; Williams 2005a: 2), but its 'basic minimum elements' (Selai and Rosser 2005: 91), 'a small “common core” of key attributes' (Williams 2005b: 239).

¹³ The three levels do not cover a dimension fully (van Agt and Bonsel 2005: 30–1).

respondent thus selects a five-digit code to describe her HRQOL¹⁴ (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 EQ-5D'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.¹⁵ The following discussion focuses on the first three dimensions. It is through the notion of life reflected by its normative claims that having no problems in mobility, self-care, and usual activities benefits QOL that 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' (Brooks et al. 2003: 283).¹⁶ The questionnaire formulates severity level 1 as 'I 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 EQ-5D 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)¹⁷ – 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' (Brooks 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

¹⁴ 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-care, 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).

¹⁵ The 'dimensions ... constitute ordinal scales in which level $i+1 < \text{level } i$ ', '<' meaning 'worse than' (Dolan and Kind 2005: 141), not necessarily 'less authentic than'. But 'the numerals 1–3 have no arithmetic properties and should not be used as a cardinal score' (Rabin et al. 2011: 4).

¹⁶ 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).

¹⁷ The definitions 'may ... contribute to an explanatory background for EQ-5D application studies', but are mainly aimed at 'researchers and translators of the EQ-5D 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 EQ-5D' (Brooks 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' (Fox-Rushby 2005: 36–7) in an 'attempt to draw out the intended meanings of the survey questions by the original developers'¹⁸ (Fox-Rushby and Selai 2003: 168). The responses on '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 yet, in walking about without any problems, depend on a stick, crutch, or walking frame. For the current version, level 2 was reformulated as 'I have some problems in walking about' (Rabin et al. 2011: 5) 'so as to not exclude people who used 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]eeds 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). 'I have no problems in walking about' is reserved for those with no problems in walking about independently without any aids.

Throughout, the EQ-5D 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 qua 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 suffers; only trouble-free walking about which is independent, free of all help and aids, accomplished solely by the individual's own body,¹⁹ constitutes a desirable mode of mobility conducive to a good quality life. The EQ-5D 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:

¹⁸ This exercise, too, was meant to aid translation (Fox-Rushby and Selai 2003: 168).

¹⁹ See also Fox-Rushby and Selai (2003: 170) and Rabin et al. (2003: 193).

The main idea conveyed was of being restricted to bed and only able to move out of bed with some help. However, the actual range of answers lay between ‘unable to get out of bed without help’ and ‘not able to go outdoors, even with help’. The majority of queries were raised about the extent of mobility and whether a person would be able to get to a toilet by themselves or not. The range of answers covered ‘use of a bedpan’, ‘can, but only with considerable help’, ‘possibly able to use toilet’ ... The notion of dependency is crucial to the question

For the most part, it is suggested that level 3 captures not only people who are restricted to staying in bed or unable to get out of bed (except to use the toilet), but additionally some who are not confined to bed yet capable of getting out of bed only with help from others. Dependence is seen as grave enough that in some cases the difference between being able and unable to get out of bed becomes unimportant if that ability depends on someone else’s assistance. So serious an encroachment on life is dependency that some of those able to get out of bed but only with help from others join those literally confined to bed as sufferers of the same infringement on the mobility dimension of quality of life.

The second EuroQol dimension is ‘Self-Care’. Two questionnaire items mention ‘washing’ and ‘dressing’ as specifications, but level 1 is simply ‘I have no problems with self-care’ (Rabin et al. 2011: 5). This phrase per se, the section heading ‘Self-Care’, and some of its translations, e.g. ‘*Körperpflege/Hygiene*’ (Schulenburg et al. 1995: 154) – ‘personal bodily hygiene’ (Rabin et al. 2003: 194) or ‘body care/hygiene’ – in the original 1994 German version, could suggest that severity level 1 includes every person without problems in ensuring that her self is cared for. Yet the category only includes the individual with no problems in caring for her self herself, independently of others. The EuroQol Group specifies self-care officially as ‘independence in daily personal care. It ... covers washing and dressing, but also includes feeding oneself, personal hygiene, brushing teeth, grooming and going to the toilet’, though ‘not ... social or role activities, or the ability to manage personal finances or household affairs’ (Brooks et al. 2003: 284). For the French EQ-5D, ‘self-care has been translated as “autonomie de la personne” which is related to independence’ (Rabin et al. 2003: 194). Responses from the surveyed EuroQol members on the meaning of ‘self-care’ indicated that ‘[t]he important underlying idea ... seems to point towards independence in basic daily care activities’ (Fox-Rushby 2005: 39).

Severity levels 2 and 3 are formulated as ‘I have some problems washing or dressing myself’ and ‘I am unable to wash or dress myself’ (Rabin et al. 2011: 5). ‘Washing self’, according to the official specification, means ‘[a]bility to take a bath or shower without help from someone else; washing whole body and not just face and hands’ (Brooks et al. 2003: 284). Similarly, the EuroQol Group’s survey respondents largely agreed that self-care ‘is about washing and dressing all parts of the body by oneself’ (Fox-Rushby 2005: 46). Levels 2 and 3, that is, include not only every individual with problems ensuring, or no ability to ensure, that her self is cared for; they also include every person who, albeit free of

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 the EQ-5D descriptive system, ‘having some problems with self-care (level 2) is worse than having no problem with self-care (level 1)’ (Dolan and Kind 2005: 141). The precise assertion here is that a desirable form of self-care, one truly conducive to a good quality of life, does not mean simply ensuring, without any problems, that one’s self is cared for (washed, dressed etc.): encountering no trouble in ensuring care for oneself does not amount to a desirable mode of self-care if that care depends on others; only problem-free care for the self by the self dependent on no other amounts to the desirable form of self-care necessary for good QOL. Similarly to ‘Mobility’, this EQ-5D dimension articulates a positive appreciation of self-care which is interwoven with a particular vision of independence and self-reliance.

It is neither indisputable that a desirable mobility level defined as ‘I have no problems in walking about’ must mean problem-free walking about independent of aids, nor is it beyond debate that a desirable self-care level defined as ‘I have no problems with self-care’ must mean problem-free care for the self by the self dependent on no other. A respondent to the EuroQol members survey, for example, argued that ‘walking about ... included “any steps taken even with crutches, walking frames or support”’ (Fox-Rushby and Selai 2003: 170). During the process of translating the EQ-5D into Shona, a major language in Zimbabwe, it emerged that the terms available for translating ‘I have no problems with self-care’ directly, ‘I don’t need anyone to help me’, would ‘come across as arrogant’ (Jelsma et al. 2000: 8). The EQ-5D, however, is oriented not only by the notion that mobility qua walking about and self-care contribute to good QOL, but also by positive appreciations of independent, self-sufficient living and a corresponding depreciation of dependency.

Such modes of ‘thinking selves’ hinge on ‘the *prior* acceptance of a particular cultural, political understanding of the nature of personhood’ (Rapley 2003: 123). The translators of the Shona EQ-5D experienced a ‘contrast to Western individualism and emphasis on self-determinism’ which ‘implies that independence in functioning is not weighted as heavily as it would be in Western cultural contexts’ (Jelsma et al. 2000: 4). There have been ‘societies’ in which ‘dependence has ... carried no hint of self-abasement’ (Sennett 1998: 140). According to Finn and Sarangi, ‘(HR)QOL’ is ‘[a]lways and already value infused as to what counts as “quality”’, and ‘it has been argued that it is predominately white, western-centric notions of health, selfhood and function that are assumed and thus reinforced by QOL measures’ (2008: 1569). The ‘development of the EuroQol’, remarks a member of the Group, ‘took place mainly in northern Europe, with an inevitable bias towards cultural concepts appropriate to that part of the world’ (Gudex 2005: 19).

The EQ-5D'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 problems of independence and dependence in a specific form. And yet in reflecting an ideal of independent, self-reliant living, these sections of the EQ-5D also resemble QOL conceptions scrutinised by other scholars as expressions of a specific positive ideal which is particularly closely related to a model of personhood whose dominance distinguishes advanced liberal culture. As early as 1998, Rapley and Ridgway (1998) asserted that the QOL construct then current in the government of the UK's intellectual disability services needed to be read in relation to, inter alia, an emphasis on disabled people's ability to attain independence and a wider Western corporatist, managerialist discourse. Rapley (2003: 124–37) reiterates this argument whilst further foregrounding the links of that sector's QOL construct with conceptions of disabled people as able 'to acquire ... "independence" and "control"' (2003: 134) and with 'the values of the enterprise culture': notably with a vision of the individual as "enterprising self", which 'furnishes a version of self as subjective being ... aspiring to independence ...' (2003: 131). Rapley's key source is Rose's (1992: 141–2) reading of a 1989 newspaper advert for self-help guidance for enhancing QOL in view of the image of 'the "enterprising self" ... now dominat[ing] "Western" political mentality' (Rapley 2003: 122). The discourse in focus in their more recent investigation of HIV-NGOs, argue Finn and Sarangi, formulates 'being self-sufficient (i.e. not dependent on welfare or charitable support)' as a precondition for QOL (2008: 1574). In gerontology, Katz and Marshall (2004: 63) highlight, 'the language of ... testing' for 'functions of daily life (toileting, dressing, eating, mobility, etc.)' 'is geared towards "independent living", used interchangeably with "successful" ... aging'. Their argument is embedded in a broader discussion of the displacement of the binary conception of the normal and the pathological by that of functionality and dysfunctionality²⁰ in the life sciences (Katz and Marshall 2004). One major part of the 'assemblage of instruments, knowledges and practices' they investigate is the 'measurability' of 'functionality as a bodily state'.

Behind the measurability of functional states lie the bio-cultural standards of enablement. It is not difficult to see their connection to prevailing neo-liberal social mandates around individualism, active and mobile life-styles, responsible self-care and economic independence. The goal of being 'functional' is often couched in a discourse of freedom, choice and adaptability (Katz and Marshall 2004: 58).

In '[n]eoliberalism ... [t]he language of the entrepreneurial individual, endowed with freedom and autonomy, has come to predominate over almost any other in evaluations of the ethical claims of ... programmes of govern[ing personal life]' (Rose and Miller 2010: 298; see also Finn and Sarangi 2008: 1570–1). In fact, Rose (1992: 159) maintains, the

²⁰ Functioning is often considered a QOL-determining factor (e.g. Schulenburg et al. 1995: 135; Reuter 2007: 251).

image of the ‘individualistic rather than ... dependent’ subject is accepted across much of today’s political spectrum. Correspondingly, the ‘so-called “dependency culture”’ forms ‘a primary target’ (Heelas and Morris 1992: 7; see also Rose 1996: 59–60; Rose and Miller 2010: 296; Sennett 1998: 139–42).

Usual activities

The third EQ-5D QOL dimension is ‘Usual Activities (e.g. work, study, housework, family or leisure activities)’. The severity levels are: 1, ‘I have no problems with performing my usual activities’, which is considered desirable; 2, ‘... some problems ...’; 3, ‘I am unable to perform ...’ (Rabin et al. 2011: 5). The section’s most obvious normative claim is that wellbeing hinges not simply on being in a certain state (e.g. pain- or anxiety-free, as suggested by the fourth and fifth sections), but on the problem-free performance of *activities*: notably work, study, housework; but family also features specifically as family activities, leisure as leisure activities – ‘*Familien- oder Freizeitaktivitäten*’ in German (Claes et al. 1998: 18). The questionnaire thus reflects a positive evaluation of active living.

Moreover, its list of usual activities suggests that the trouble-free performance of *work* – and arguably productive – activities benefits QOL. Work, study, and housework are conceived as ‘work activities’ (Williams 2005a: 2) and thus appear to be assigned to the realm of production. Incidentally, the work activities seem to have had a somewhat privileged status in the development of the EuroQol system. The questionnaire’s initial version, the EQ-6D, contained six dimensions, some with only two severity levels. Among them were ‘Main activity’ – ‘1. Able to perform main activity (e.g., work, study, housework)’/‘2. Unable ...’ – and ‘Social relationships’ – ‘1. Able to pursue family and leisure activities’/‘2. Unable ...’ (EuroQol Group 1990: 204). Insofar as the former and the latter set of activities each had their own dimension, they had equal priority. Yet only work activities were listed as examples of somebody’s *main* activity. Shortly after publishing the EQ-6D, though, the Group reduced the number of QOL dimensions to five. ‘Main activity’, the dimension containing only work activities, was kept and renamed ‘Usual activities’, retaining work, study, and housework as examples. By contrast, ‘[i]t was finally agreed to take out “social relationships” – the dimension containing the other two activities – as a separate dimension ... It was subsumed under what was previously the “main activity” dimension, which was changed to ... mention family and leisure activities alongside work, study and housework’ (Gudex 2005: 25).²¹ Due to the addition of ‘family or leisure activities’ to ‘work, study, housework’, the EQ-5D’s emphasis on usual activities entails a softer accent on the QOL benefits of work and productive activities than the EQ-6D’s emphasis on main activity if the two dimensions are compared in isolation. Nonetheless, the EQ-5D’s stress on the contribution of a problem-free performance of ‘usual activities’

²¹ Members’ accounts of the Group’s reasons for modifying the questionnaire in this way differ in the detail (Gudex 2005: 23–5; Williams 2005a: 2), but concur on the weight of the insight that “social relationships” ... contribute[d] little to the valuation of health states’ (Gudex 2005: 25; see also Williams 2005a: 2).

to a good QOL implies a positive appreciation of work – and arguably productive – activity.

Finally, this section of the questionnaire suggests that good life quality depends on problem-free acting and functioning in, and relating and contributing to, one's social surroundings. While the official definition of 'usual activities' seems to frame only 'family activities' as 'social activities' (Brooks et al. 2003: 284), the EQ-6D understood the pursuit of 'family and leisure activities' as 'social functioning' and subsumed it under 'Social relationships' (Gudex 2005: 22). In the EQ-5D, 'social functioning' is 'encompassed ... in the "usual activities" dimension' (Brooks and EuroQol Group 1996: 56). This dimension, Schulenburg et al. specify, covers '[s]ocial functioning', which 'includes the ability to have social contact and related activities', e.g. 'with friends and relatives', as well as 'role functioning', which comprises "'formal employment, school work and housework'" (1995: 146). Since Schulenburg et al. define both concepts partly with reference to Ware (1987: 478), for whom 'social functioning' and 'role functioning' are 'distinct' and 'should be measured and interpreted separately prior to aggregation' (1987: 475), it seems that the EuroQol Group does not consider work, study, and housework social activities. Usual activities is officially defined as 'activities such as work (paid and unpaid), study, housework, leisure and social activities' (Brooks et al. 2003: 284), and the respondents to the above mentioned survey named 'social activities' as one aspect of 'usual activities' alongside 'work, study, leisure' (Fox-Rushby 2005: 40). And yet the instrument subsumes work, study, housework, family and leisure activities under the same dimension, rather than measuring any or any set of them separately, so any distinction the Group may have drawn between role functioning and social activities is not particularly consequential. Indeed, it is hard to imagine an individual performing the roles of work, study, or housework who is not simultaneously performing activities within a social context. For instance, performing paid work means entering an exchange relationship, whilst performing unpaid work, like performing housework, often means making contributions to a community or society. Ultimately, the EQ-5D seems to articulate a positive appreciation of various ways of becoming involved in, and contributing to, the social surroundings in which an individual lives.

In expressing an appreciation of active living, work and productive activities, and social involvement, the EQ-5D's treatment of usual activities also resembles QOL frameworks previously analysed as expressions of specific positive evaluations especially closely associated with the model of subjectivity whose prominence marks advanced liberal culture. In the discourse studied by Katz and Marshall, 'the objective of enabled functional states is *doing* rather than *being* ... , to *do* school, work, family, etc., without becoming dependent on social programs to do so'. '[A]ctive ... life-styles' (2004: 58) and 'activity', like 'independence', they add, form the substance of 'neo-liberal mandates' (2004: 68). In fact, Rose argues, in advanced liberal democracies 'all shades of political opinion ... agree that citizens *should* be active and not passive' (Rose 1992: 159; see also 1996: 59–60; Heelas and Morris 1992: 2; Rose and Miller 2010: 298). In this analysis of the model of the

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] self-fulfilling impulses’ (1992: 154).²² 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]hese newly minted “enterprising selves”, it is suggested, will too come to find their subjectivity enhanced by producing and consuming’ (Rapley 2003: 133). The discourse scrutinised by Finn and Sarangi separates ‘QOL’ from ‘laziness’, which ‘is constructed as a kind of self-defeating and irresponsible inertia that involves not working, relying on welfare and waiting to die’ (2008: 1575). The QOL arguments Reuter has investigated²³ also reflect the ideal of an ‘independent’ and ‘productive’ existence (2007: 251). Moreover, they reflect a positive notion of becoming ‘contributing members of society’ (Reuter 2007: 251). Similarly, adding to the point that disabled individuals will benefit from paid work, the policy document quoted in Rapley’s study notes that “it is important that the country makes the best use of the skills and potential contribution from all its citizens” (Rapley 2003: 133, citing the UK Department of Health). ‘Within th[e] new regime of the actively responsible self’, argues Rose, ‘individuals are to fulfil their national obligations ... through seeking to *fulfil themselves* within a variety of micro-moral domains ... – families, workplaces, schools, leisure associations, neighbourhoods’ (1996: 57; see also 1992: 152).

Summary

The EuroQol Group has long ‘pointed out ... that [its] work ... has been “culture-specific” with a focus on concepts common to “western” cultures’ (Brooks and EuroQol Group 1996: 56). ‘HRQoL instruments ... are “culture-full”’ (Fox-Rushby 2005: 48). Fox-Rushby and Parker state that ‘researchers are possibly the most influential group of people in the development of generic instruments’ (1995: 258). Devices such as the EQ-5D ‘reflec[t], in particular, the beliefs and values of the researchers who contributed to their construction’ (1995: 257, see also 262–3). ‘Given the influence of the researchers in defining HRQL or

²² Miller and Rose (1995: 453–4) found that in the 1980s, when the perceived ‘neglect of the values of autonomy, entrepreneurship, and individual self-motivation’ came to be deemed especially problematic, the notion of ‘the worker [a]s an individual seeking to fulfill him- or herself through work, and work [a]s an essential element in the path to selffulfilment’, gained particular currency in the government of the workplace.

²³ Partly drawing on Katz and Marshall (2004), Reuter (2007) analyses the legal discourse enveloping ‘wrongful life’/‘wrongful birth’ malpractice suits filed by parents of children with the genetic disorder Tay-Sachs disease. Prospective parents are assigned the ‘right to be responsible’ and have their ‘genetic status’ inspected in order to take an ‘informed decision’ about pregnancy termination (2007: 238–48). This is deemed indispensable to ensuring that unborn children with bad prospects can avoid lives of exceptionally poor quality (2007: 245–53): ‘not to have been born at all’ is associated with a higher QOL than living with Tay-Sachs (2007: 248). QOL is determined by pain and functioning ‘bodily processes (sight, hearing, mobility, etc.)’ as well as by the ‘ability to optimize one’s corporeality’ and by becoming an ‘independent, productive, contributing’ citizen (2007: 251). Reuter warns against narrowly focusing on agency in such decisions, since choice is socially restricted and a social obligation (2007: 238–40, 254–7; see also 2012).

categorising dimensions, it is important to consider who the researchers are, and contemplate which factors’ – e.g. research ‘disciplines’, ‘level of education’, wealth – ‘may be affecting their ... perceptions of HRQL’ (1995: 260). Oriented by enquiries into other QOL frameworks (Finn and Sarangi 2008; Katz and Marshall 2004; Rapley 2003; Rapley and Ridgway 1998; Reuter 2007), the above considerations have illustrated a way of further contributing to studies of the EQ-5D as a ‘cultural instrumen[t]’ (Fox-Rushby and Parker 1995: 261) which focuses on unearthing the content of its formulations and normative claims in detail, so as to specify the substance of the ideals it reflects, and on asking which prevalent modes of thinking persons these ideals might be linked to.

Reducing the EQ-5D and the broader ‘research programme’ of the ‘EuroQol “enterprise”’ (Brooks 2003: 1) to vehicles of visions of independence would amount to nonsense. Most conspicuously, perhaps, the EuroQol conception of extreme pain and anxiety as undesirable attributes of life appears to express chiefly that life should not feel pain and anxiety. Incidentally, whilst the questionnaire thus certainly resembles other QOL frameworks that express similarly general, negative responses to pain and fear, these cannot, in turn, be said to have an exceptionally close affinity with the model of subjectivity whose prominence characterises advanced liberal thinking. It should also be noted that a study of the ideals articulated by QOL questionnaires is not equivalent to a study of the notions that shape patients’ categorisation of their health by means of such tools. This is especially pertinent to the EQ-5D, which ‘is designed for self-completion by respondents’ (Rabin et al. 2011: 3).

However, what is decisive in this context is that according to NICE’s method for cost-effectiveness assessments of treatments, QOL weights for QALY calculations are ideally informed by patients using EQ-5D to describe their health’s QOL aspects. The Institute’s procedure thus supports the responsabilisation of the patient for observing and reporting on her HRQOL and reflects positive appreciations – namely those expressed by the device’s normative assertions about QOL in its first three sections – of active living, work activities, social involvement, and a specific form of independence and self-sufficiency.

... in dependence

The second step towards establishing QOL weights for computing QALYs, according to NICE’s cost-effectiveness analytical approach, involves asking the *public*, rather than patients themselves, carers, or health professionals, to *value* health states with a view to the QOL characteristics attributed to them by patients using the EQ-5D. A representative sample of the UK population evaluates a health state with reference to its patient-generated EuroQol classification, which consists of one statement in each of the questionnaire’s five sections and articulates a combination of one severity level – no problem or some/moderate problems or extreme problems experienced by patients – per dimension. Valuation means assigning QOL weights between negative values – worst possible health – and 1 – best

possible health – with 0 assigned to (equivalence with) being dead²⁴ (Brazier et al. 2005: 201; Dolan et al. 1996; 2009; NICE 2008a: 38–9; 2010a; see also Brazier et al. 2007).

The public as consumer

A QOL weight stands for a subjective evaluation of a health state in respect of the patient's QOL properties experienced by her and articulated through EQ-5D. More precisely, the weight represents an evaluation of that health state by a subject imagining itself 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: 2) or 'preference weight[s]' (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* for, 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 EQ-5D.²⁵

Citing 'evidence of significant discrepancies in health state values by illness experience', Brazier et al. (2005: 202) note that choosing between the public's 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 – calculating QALYs as life years times QOL weights – assigns the public a key role in determining how many extra QALYs/£ a treatment yields. The public is centrally involved in determining a treatment's cost-effectiveness and thus strongly influences NICE's decision whether to recommend a treatment for NHS spending. Public judgement is an important factor in establishing whether a technology is calculated at above £30,000/QALY gained, and therefore whether an ever 'stronger case' is needed 'for supporting' it as an NHS investment (NICE 2008b: 19; see also Brazier et al. 2005: 202, 205).

The debate about whose subjective health state valuations should count in this context assembles several arguments for and against prioritising the public's views and for and against prioritising those of patients (see e.g. Brazier 2007: 6–7; Brazier et al. 2005; 2007:

²⁴ For instance, the public might give a health state in which patients describing its QOL features have chosen code 22112 – meaning patients experience some/moderate problems in the mobility, self-care, and anxiety/depression domains and no problems in usual activities and pain/discomfort – a QOL weight of circa 0.65 (Dolan 1997: 1105).

²⁵ NICE's reference case states that QOL weights should reflect 'public preferences elicited using a choice-based method' (2008a: 38). Time trade-off, standard gamble, and other methods (see Brazier et al. 2007: 83–111) deserve separate attention.

112–17; Dolan et al. 2009; Gold et al. 1996: 98–106; Nord et al. 2005; Rapley 2003: 145). The recommendation to incorporate QOL weights containing the public’s evaluations into public sector cost-effectiveness assessments of health spending options is generally justified from at least three angles: since, firstly, the public as taxpayers fund, and, secondly, as potential patients might all one day receive, healthcare and its effects, their preferences for its HRQOL implications should determine the weights used and shape decision making (Devlin and Parkin 2007: 44–5; Rabin et al. 2011: 19; see also Brazier et al. 2005: 204; Dolan et al. 1996: 141). Thirdly, scholars cite the “veil of ignorance” image: ‘where “a rational public decides what is the best course of action when blind to its own self-interest, aggregating the utilities of persons who have no vested interest in particular health states seems most appropriate”’ (Brazier et al. 2005: 204, citing Gold et al. 1996: 100; see also Gold et al. 1996: 6–7, 35; Brazier 2007: 7; Devlin and Parkin 2007: 44). However, ‘[t]he main argument for using the general public to value health states hinges on the view that in a publicly funded health care system it is society’s resources that are being allocated, and therefore it is the views of the general population that are relevant’ (Brazier 2007: 7).²⁶

The valuation exercise and the concept of QOL weights in NICE’s cost-effectiveness analysis framework suggest a notion of members of the public as consumers of commodities. Owing partly to their role as taxpayers with a budget funding the health system, citizens are empowered to voice their subjective HRQOL preferences and help choose healthcare products and their effects for patients – and thus for those citizens *qua* potential patients who will be actual patients one day – for NHS purchasing (see also Lupton 1995: 68–9). NICE’s work seems here to continue to resemble QOL frameworks analysed elsewhere as reflections of values especially closely related to the model of subjectivity whose prominence distinguishes advanced liberal culture. The QOL construct deployed in the government of the UK’s intellectual disability services, argues Rapley (2003: 130–7; see also Rapley and Ridgway 1998; Finn and Sarangi 2008: 1570–1), is linked to a construction of persons with intellectual disabilities as potentially autonomous “consumers”/“customers” able to voice their ‘preferences’ (Rapley 2003: 134) and ‘choose between “packages of care”’ understood as a ‘commodity’ (2003: 131–2). This construction has affinity with the contemporary model of the “enterprising self” ... with subjective wishes and preferences’ (2003: 135) ‘seeking fulfilment th[r]ough ... acts of choice’ (2003: 131). Neoliberal ‘programmes for the government of personal life’, Rose and Miller (2010: 298) hold, are oriented by the ideal of a ‘sphere of freedom ... where autonomous agents ... pursue their preferences’. In conditions of advanced liberalism more generally, ‘[t]he enhancement of the powers of the client as ... consumer of health services, ... education, ... training, ... transport ... specifies the subjects of rule ... as active individuals seeking ... to maximize their quality of life through acts of choice’ (Rose 1996:

²⁶ This resonates with NICE’s (2008b: 10) view that ‘[t]he NHS is funded from general taxation, and it is right that UK citizens have the opportunity to be involved in the decisions about how the NHS’s limited resources should be allocated’.

57, see also 41; 1989: 227; 1992; Heelas and Morris 1992: 1–8). The vision 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.'s (2009; cf. Speight and Reaney 2009) legitimate rejection of the claim that NICE does not consider patients' views needs 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 in – engaging patients²⁷ (Amis 2009; Kelson 2009: 10–11; NICE 2004a; 2007: 18–19, 36).

Nor are patients' contributions to NICE technology appraisals reducible to ticking EQ-5D boxes. Patients can suggest guidance topics (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 the two items: a definition of questions, technologies, clinical problems, patient groups, outcomes etc. and a list of stakeholders invited to participate in the appraisal (Amis 2009: 31–2; Kelson et al. 2009; NICE 2004a: 11–13, 35–6; 2008a: 8–13; 2009: 12–16; Quennell 2001: 212; Schlander 2007: 29–30; Walker et al. 2007: 53). 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). Consultee organisations have the opportunity to submit written evidence – including patients' views on the consequences of a condition and a technology for their lives and on what the key outcomes are – which the appraisal committee will review when developing recommendations (Amis 2009: 32–3; NICE 2004a: 6, 16, 29–31; 2008a: 22–3; 2009: 18–19; Quennell 2001: 212; Walker et al. 2007: 62). Moreover, the committee considers participating patient organisations' comments on the assessment group's assessment report (NICE 2004a: 18; 2009: 28; Schlander 2007: 35). Participating patient organisations can also nominate 'patient experts' with experience of the condition or the technology under inspection to attend the first appraisal committee meeting; selected experts submit written personal statements and, during the meeting, raise and answer questions, provide further information, and voice concerns (Amis 2009: 33; Kelson et al. 2009; NICE 2004a: 17, 23–5; 2008a: 26, 55; 2009: 29–31, 34, 59; Quennell 2001: 212). The committee itself includes 'members ... from ... lay backgrounds (with an understanding of patient and public perspectives on healthcare issues)' (NICE 2009: 6; see also 2004a: 7; Amis 2009: 33; Littlejohns et al. 2009: 181). Finally, patient organisations can shape the outcome of NICE appraisals by commenting on the appraisal committee's provisional recommendations and – as consultees – by appealing against the final recommendations (Amis 2009: 34–6; Kelson et al. 2009; NICE 2004a: 20–

²⁷ For an early, critical study of patient organisations' interactions with NICE, see Quennell (2001).

1, 27; 2008a: 59–60; 2009: 5–7, 36–43; Quennell 2001: 212; Schlander 2007: 35–6; Walker et al. 2007: 54).

NICE thus offers patients several further opportunities to bring experiences and views of, and evidence, statements, and comments on, a technology, a condition, and their impacts on patients' lives to HTAs. In this sense, its notion of the patient's role remains consistent with the aforementioned trend in the development of contemporary healthcare governance identified by sociologists: the ever wider acceptance of the idea that, rather than simply 'receiving ... ministrations', patients should 'be ... engaged in the administration of health', 'organize and represent themselves in the struggles over health', and articulate their health 'experiences' (Rose and Miller 2010: 293; see also Rapley 2003: 139–40). NICE are 'looking for patient experts who ... will be confident in the Committee meeting' (2004a: 23).

Nonetheless, NICE's recommendations hinge on assessments of technologies' cost-effectiveness, which should follow its reference case (2004b: 7, 26; 2008a: 4, 8, 19, 21, 27, 31; Schlander 2007: 31; Walker et al. 2007: 54).²⁸ 'For the reference case', as mentioned, 'the value of changes in patients' HRQL (... utilities) should be based on public preferences' (NICE 2008a: 38; see also Brazier et al. 2005: 201; Schlander 2007: 31; Walker et al. 2007: 55).²⁹ Again, the fact that 'NICE prefers ... cost utility analyses [to] use utilities deriving from general population values rather than from patients who have direct experience of the particular medical condition' does not indicate that NICE 'doesn't consider the patients' perspective', as Speight and Reaney (2009) seem to suggest. It means that NICE assigns the public an important role in determining how many QALYs/£ a technology produces and thus considerable leverage on NICE's decision about whether or not it will recommend the technology for NHS investment.

Health state utility values ... are one of the key parameters in cost effectiveness models and have been found to have a major impact on the results of many appraisals (Brazier 2007: 2).

In most instances, a technology will not be recommended if there is a lack of evidence for its clinical effectiveness or if the technology is not considered to be a cost-effective use of NHS resources, compared with current NHS practice (NICE 2010b).

²⁸ NICE is allegedly 'becoming increasingly prescriptive about different aspects of the methods of economic evaluation' (Brazier et al. 2005: 201) and 'has arguably the most prescriptive guidelines among national technology assessment agencies' (Griffin et al. 2008: 137). 'Submissions to the Institute', NICE states, 'should include an analysis of results generated using th[e] reference-case methods. This does not preclude additional analyses being presented when one or more aspects of methods differ from the reference case. However, these must be justified ...' (2008a: 31).

²⁹ Health state 'values ... from the general population's perspective' were provided 'in 77% of submissions' between 2004–2008 analysed by Tosh et al. (2011: 105).

For NICE, choosing ‘whose preferences to use for valuation of health outcomes’ constitutes ‘essentially’ a ‘value judgemen[t]’ (2008a: 31; see also Brazier 2007: 7). Now, NICE’s mode of procedure for cost-effectiveness assessments of health technologies reflects a normative conception of the patient’s life already by virtue of its first step towards determining QOL weights for QALY calculations. The enrolment of patients for describing their HRQOL and other areas of NICE’s work involving patients articulate the responsabilisation of the patient for observing her own health and reporting her experiences. This is consistent with the already mentioned wider rejection of the idea of a patient who is passively receiving healthcare in favour of a vision of patients involved in health management (Rose and Miller 2010: 293). The EQ-5D device at the heart of NICE’s framework, in turn, reflects particular conceptions of active and, most insistently perhaps, of self-sufficient, independent living.

By dint of the second step towards establishing QOL weights for QALY computations, however, NICE’s cost-effectiveness assessment framework adds another key dimension to its construction of the patient’s position. Precisely to the extent that – in enlisting the general public to value and ascribe QOL weights to health states – NICE’s framework assigns the public with the healthcare budget the position of the consumer who expresses subjective health preferences to help choose healthcare products and their effects for patients for NHS funding, it constructs a position of passivity and dependence for patients. Where patients describing their HRQOL are not simultaneously asked to conduct the valuation exercise and thus given the influence on NICE’s decisions whether to recommend funding treatments that the public currently has, theirs remains largely the position of passive recipients of health technologies and effects which the taxpaying public, consulting their health preferences, helps choose for NHS investment. The UK Health Department’s 2001 vision for “‘today’s patients with chronic diseases’”, that they “‘can become key decision-makers in the treatment process’” and “‘need not be mere recipients of care’” (cited in Rapley 2003: 139), is only to a limited extent congruent with the conception of the recipients of technologies undergoing NICE appraisal emerging here. NICE (2008b: 8) ‘recognises the rights of individuals to make informed choices about healthcare ... From this arises the concept of “patient choice”. The moral principle of respect for autonomy cannot, however, be applied universally or regardless of other social values’. By virtue of its valuation component, NICE’s cost-effectiveness analytical procedure thus inscribes patients into a relationship of dependence on the public’s preferences. According to this conception, whether or not the patient’s length and/or quality of life, including her independence from aids or the help of others, is improved through the health service’s provision of technically available health products is dependent on the taxpaying public’s stated health preferences, which are to inform the selection of health technologies and effects for NHS investment. In light of some of the aforementioned critical analyses of healthcare frameworks around life quality (Finn and Sarangi 2008: 1570–1, 1574–5; Katz and Marshall 2004: 58, 63, 68; Rapley 2003: 124–37; see also Rose 1992: 159; 1996: 57; Rose and Miller 2010: 298), one may surmise that the currently dominant model of autonomous personhood associated with the ideal of the patient’s

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 other scholars, too, inscribe individuals into dependencies, albeit in quite different ways. As noted at the 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: 1574–5). Similarly, the functionality discourse Katz and Marshall have deciphered with a view to the objective of independence it reflects (2004: 58, 63) simultaneously constructs dependency relations: ‘the d[ys]functional person is ostracized if he or she resists [professional] treatment or any technically assisted program leading to enabled and adjusted normalcy’ (2004: 59). People depend on receiving such treatments and on such programmes for a functional, enabled, indeed independent life which avoids exclusion.³⁰

Conclusion

It might be interjected that the matters NICE’s work raises are more straightforward than they appear. In enlisting the public for health valuation, NICE’s cost-effectiveness assessment framework does not relieve the taxpaying public of the obligation to fund healthcare products for patients. However, the ‘ultimate “payer” of the NHS, the public, the taxpayer, the potential patient’ (Littlejohns et al. 2009: 183) is not obliged to contribute to the choice of healthcare products and their effects on patients for NHS funding in line with actual patients’ own explicit health preferences or needs. This could be read as signalling a case for patients seizing the position of consumers who select treatments and effects on the basis of their own preferences – for example buying insurance or healthcare privately – and thereby leaving the position of largely passive recipients of health technologies and effects which the taxpaying public, stating their preferences, helps choose for NHS investment. Such a case may seem timely: ‘[t]he theme of enterprise ... at the heart of neo-liberalism’ – of ‘[p]erhaps the most explicit statement of [the] new forms of political rationality’ –

³⁰ Reuter’s study mentioned earlier, in turn, proceeds to reveal how the legal discourse about Tay-Sachs delineates dependency relationships. According to several arguments examined by Reuter, prospective parents cannot realise responsible conduct by themselves: no more familiar with genetics than “‘mere” laypeople”, they are ‘entirely dependent upon the ... knowledge and authority of their physicians’ (2007: 253) – upon the provision of medical information and the application of professional skill – for understanding that screening is possible and advisable, for being screened successfully, for learning the results, and hence for making educated choices regarding abortion (2007: 238–53). Insofar as this discourse portrays unborn children with poor prospects as dependent on such choices for avoiding extremely low quality lives, it frames their escape from a dysfunctional existence incapable of optimisation which will never be independent as completely dependent on that authority.

corresponds with the replacement of ‘the themes of collective provision and social solidarity’ with ‘proposed notions of security provided through the private purchase of insurance schemes’ and ‘health care purchased by individuals and provided by the health industry’ (Rose 1989: 226; see also 1996: 58). Moreover, such a case would suggest that patients should leave their position of dependence on the public’s preferences: that whether or not the patient’s length and/or quality of life is improved through the purchase of technically available health products ought not depend on the taxpaying public’s stated health preferences and their influence on the selection of health technologies and effects for NHS investment anymore. But since there is little evidence that NICE’s work is de facto inspired by such a case, this reading creates the danger of undue simplification.

By virtue of its two core components, the Institute’s procedure for the cost-effectiveness assessments that are to shape its recommendations for decisions on NHS health technology funding reflects a more multifaceted construction of the patient’s position. NICE’s enrolment of patients in HRQOL description exercises designed by the ‘EuroQol enterprise’ (Gudex 2005: 19) lends a voice to notions consistent with the wider depreciation of the patient as a passive healthcare recipient as well as to a particular ideal of self-sufficient, independent living; its enrolment of the public in health valuation constructs for the patient the position of a to a considerable extent passive recipient of health products and effects who depends on the public’s preferences. The Institute’s work raises and expresses these issues in partly quite specific ways; but not only do the notions of independence and dependence, like in other areas, throw the situation NICE’s procedure constructs for the patient into sharper relief, this multifarious construction itself also resonates with QOL frameworks assessed elsewhere (Finn and Sarangi 2008; Katz and Marshall 2004; Rapley 2003; Rapley and Ridgway 1998; Reuter 2007).

It is perhaps unsurprising that in the health system, especially in the context of decisions on how to channel scarce resources, conceptions of the patient’s position eventually point to questions about her independence and dependence. What NICE’s cost-effectiveness assessment framework and QOL conceptions in other healthcare areas indicate is that the health sector’s construction of the patient’s position is far from straightforward, particularly with regards to questions about what the patient should be independent from and whom she may depend upon, which dependency relations ought to be avoided, which must be established, severed, accepted or maintained – and under which conditions. Moreover, these frameworks underscore the weight of the health sector’s answers to such questions in the social organisation of healthcare. Close examinations of quality of life frameworks in their health regulatory settings with a view to the lives, situations, and positions envisioned and created for individuals promise timely contributions to the characterisation of the modes in which healthcare is governed and patients are treated today.

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