

# NICE or nasty—discuss?

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NICE was established by the former Health Minister, Frank Dobson in 1999. Its website quotes its remit as “an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.” It was to “ensure everyone has equal access to medical treatments and high quality care from the NHS—regardless of where they live in England and Wales”.<sup>1</sup> It was hoped that the post-code lottery would be consigned to the dustbin of history!

Many of its recommendations have been welcomed. However, as time has progressed, less popular decisions have been made, attracting the criticism of patient groups, and specialists who feel that their independence has been threatened. Increasingly, these decisions have been predicated on “cost-effectiveness”, rather than effectiveness per se. Herceptin® in breast cancer; cholinesterase inhibitors in Alzheimer’s disease, and the treatment of Wet Macular Degeneration have all attracted much criticism, debate and campaigning from patient groups and specialists with a surrounding media furore with each one. However, are these criticisms fair?

Firstly, we all acknowledge that there must be a point at which expenditure on a single patient or small group of people with rare but expensive needs must be balanced against the need to utilise a budget to the benefit of the

majority. Traditionally, this has been attempted by use of Quality Adjusted Life Years—a crude determinant of value, and one believed by many to be prejudicial to elderly and chronically ill patients (as opposed to younger, economically active subjects with acute or reversible illnesses). When it is suspected that one strategy may be more effective but also more costly, then the incremental cost-effectiveness ratio is recommended.<sup>2</sup> However, as most older people in the UK have been paying National Insurance and taxation into the support of the NHS all their working lives, then a value judgement that does not recognise their contribution could be deemed unfair.

Secondly, who determines these calculations, and what is taken into account? We observed a rather uncomfortable wriggling of NICE over the issue of cholinesterase inhibitors in Alzheimer’s disease, with their most recent determination agreeing with many of us who had argued in favour of a therapeutic trial in suitable patients regardless of the (utterly useless, in my view) rationing tool of the Mini-Mental State Examination. This gave a bogus cost-effective argument for their use only in people scoring between 10–20 on this arbitrary test, and denied patients in the earlier years and with lesser impairments (as measured by this tool), but potentially greater stress to themselves and their carers as they come to terms with both the

diagnosis and its implications.

I was proud to be a member of the NICE Guidelines Group for Parkinson’s disease<sup>3</sup> that supported an individualisation of therapeutics—taking on board patients’ wishes and expectations in the choice of pharmacotherapeutic options.

The original precept of NICE was not to look at “cost-effectiveness” but rather at “health”—encompassing both physical and mental aspects, and also foster a sense of well-being. The removal of choice, based on incomplete and potentially erroneous calculations based on ageist principles would undermine its authority and independence. I hope my views are representative, and that the policy makers will uphold the rights of individuals to be involved in those choices rather than be subjected to a “one-size-fits-all” policy in any future determination that denies them recognition of their individual needs, wants and expectations.

As for post-code lotteries—just as Camelot launches a new scratch card at regular intervals, new local commissioning arrangements compound the lottery, and the post-code remains a dominant force in the determination of who gets what healthcare, where, and when!

1. [http://www.nice.org.uk/aboutnice/whoweare/who\\_we\\_are.jsp](http://www.nice.org.uk/aboutnice/whoweare/who_we_are.jsp) accessed 6th October 2011-10-06
2. <http://www.nice.org.uk/niceMedia/pdf/GuidelinesManualChapter8.pdf>
3. <http://guidance.nice.org.uk/CG35>