

## Call for evidence - How does society use evidence to judge the risks and benefits of medicines?

Mrs Thatcher's dictum that "there is no such thing as society" both made and missed a point. The "society" she objected to is in general usage a collective noun for people who are doing or saying what they are told to by whatever élite controls the relevant governance and media. What she did not recognise are the other societies – of people who as individuals share an interest or problem. The distinction is particularly germane to the National Health Service. For the NHS, patients are societies of individuals but the organisation has come to aim for the benefit of "society" as represented by politicians acting ostensibly in the interest of taxpayers.

The NHS was created as a service to provide to poor people what rich people can always enjoy, namely health care that meets their personal and individual life goals and hopes. Exemplified in the agency of NICE, successive governments have transmuted the NHS from such a service into a branch of Public Health the aim of which is to maximise the capability of individuals to serve the purposes of the State ("society"). The polarity is exemplified in the use of Quality Adjusted Life Years. In a service model, individuals would decide for themselves what constituted quality, and this can be done using personalised quality of life (QOL) measures such as the SEIQUOL. A standardized one-size-fits-all measure of QOL treats patients as if they were uniform commodities like motor cars, and all of similar make. The probable fact that the "society" of middle-class taxpayers with private health insurance is happy for this to happen does not alter the individual injustice on others brought by such calculus.

NICE was originally conceived, reasonably enough, as a coordinating agency for appraising evidence on the efficacy of treatments. Soon after its creation, NICE was perverted by the insertion of economic measures of efficiency into its remit. This offloaded on to it decisions about value rather than efficacy that are properly the direct responsibility of ministers of democratic government. (Predictably, ministers can and do still interfere with NICE's decisions when it suits their interests in responding to lobbying or media campaigns). This led, on the advice of health economists representing the "society" of the middle classes, to the adoption of a fundamentally inappropriate version of QOL with its link to the discriminatory concept of Quality Adjusted Life Year (QALY). The QALY as used does not measure anything of relevance to an individual patient; it is in fact a device for blocking the input of patient preferences to clinical decision making.

Individuals who are able to appraise and demand (and pay for) care to meet personally defined values and goals will often want interventions – or withholding of interventions – that differ from what "society" prescribes. To succeed, such individuals have to be combative or rich but do nowadays have access to far more information about treatments and their effects than did their predecessors. However, the information readily available commonly does not meet the needs of an individual seeking individually desirable treatment. A prospective patient is less interested in the incidence of, say, the side effects of chemotherapy, than in what such side effects actually feel like and how they would interfere with his or her way of life. Such evidence is rarely available in unbiased and systematic form. Patient support groups have been valuable in helping individuals decide about undergoing some procedures such as colostomy, but with interventions like chemotherapy such support will only be available from survivors; the testimony of the dead would perhaps be more informative. Observation of my own patients and of friends and

family suggests that seeing what happens to other people carries a lot of weight in determining individual decisions, but samples are usually too small for useful appraisal of likely personal experience. There is surely scope for systematic and unbiased collection of data on the personal experiences of people undergoing or refusing challenging treatments. There are initiatives in place to collect anecdotal information about people's experiences in the NHS but a more systematic and analysable data-gathering is desirable. Treatment, or non-treatment, should be an informed decision by the patient not by a protocol based on what has happened on average.

My "evidence" therefore starts from a protest against the implicit limitation in the Academy's terms of reference to how decisions are made by "society". It continues into a plea for more thinking about how the society of individuals needing health and social care can be empowered to determine how their personal values can be represented in their choices of such care.

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