

Utilities vs. Rights to Publicly Provided Goods: Arguments and Evidence from Health-Care Rationing.

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Utilities vs. Rights to Publicly Provided Goods: Arguments and Evidence from Health-Care Rationing.

This paper challenges the QALY maximising approach to rationing health care on the grounds of the approximately utilitarian moral framework on which it is based. An alternative methodological approach is suggested and, in addition to consequences, four normative determinants of health-care entitlements are identified: rights, public opinion, social contracts, and community values. Survey evidence is presented showing support for these alternative frameworks and a rejection of consequentialism. The paper suggests that a (if not the) major challenge facing the designers of rationing guidelines is that of pluralism: i.e. the need to integrate considerations from a set of frameworks.

INTRODUCTION.

In recent years the rationing debate has become one of the most salient in health services research. It is often claimed that an ageing population, coupled with technological advances, have combined to create cost pressures in the UK National Health Service (NHS) to the extent that explicit rationing of services is inevitable. It is somewhat ironic, however, that as changes in health care systems (for example the Oregon experiment, the UK's internal market and work in various European countries) provide an opportunity for such explicit rationing, so moral philosophers, Korsgaard (1993) and Scheffler (1988), and economic theorists, Sen (1979, 1985) and Kolm (1994,1995), are dispensing with the utilitarian theory that underpins, some claim, the applied economic tools that provide a basis for rationing.

The most conspicuous contribution of economics to this debate is in the concept of the Quality Adjusted Life Year (QALY). This concept recognises that people value medical interventions for the benefits they bring both to length of life and quality of life. The QALY is thus a *measure* which incorporates both of these aspects of benefit. Whilst there have been criticisms of the QALY as a measure of health gain¹ these considerations are excluded from the present discussion since our concern here is with the *decision rule* of QALY maximisation. Therefore, for our purposes, health maximisation will be assumed synonymous with applying the QALY maximisation rule.

The proponents of QALYs have generally advocated that the aim of a rationing frame should be to maximise the total number generated, since this is in keeping with an economic interpretation of efficiency, Williams (1996), but there has been little examination of the relation to utilitarianism or alternative normative frameworks, despite the fact that without such examinations it is often difficult to see whether objections help establish a coherent foundation for some alternative approach, or whether they merely identify conflicting goals that have, inevitably, to be traded off. In health economics the usual moral framework associated with QALY maximisation is utilitarianism though there is some

¹ Burrows and Brown (1993) survey a number of pertinent objections based on concerns about the reliability and validity of the QALY measure. These considerations are excluded from the present discussion since our concern here is with the acceptability of the QALY as a rule: a discussion which precedes consideration of the QALY as a measure.

recognition that these terms are not coterminous, for example Wagstaff (1991) and also as well as the discussion of evaluation foundations in Birch and Gafni (1992). Utilitarianism selects the outcome which maximises the sum of peoples' preferences while QALY maximisation maximises the sum of patients' quality adjusted life years. If QALY maximisation were to be an articulation of utilitarianism, one would need to argue for a very close link between utilities and QALYs.

Utilitarianism and QALY maximisation are in fact distinct species of consequentialism, since they both yield a social ranking on the basis of valuations of states of affairs but the latter operates on preferences for health states rather than complete preferences. A successful criticism of utilitarianism does not, therefore, logically entail a rejection of QALY maximisation though a criticism of consequentialism does, reinforcing the merit of focusing on non-consequentialist issues.

This paper looks at the problem of priority setting at a fairly high level of aggregation². It is assumed that consequences cannot be entirely excluded from the determination of health-care entitlements and the central issue in rationing concerns the extent to which other considerations should be included. The structure is as follows. Section I presents three objections to the health maximisation approach whilst section II explores the potential role that alternative moral frameworks might play in grounding an explicit rationing system. A survey of voter preferences is used to test these theories with methods and results presented in section III. Concluding remarks are contained in section IV.

I. OBJECTIONS TO HEALTH MAXIMISATION

In this section, three objections to the health maximisation doctrine are discussed. The first concerns a generalised rationing problem in which the incorporation of QALY differences into the decision rule leads to allocations that entail potentially arbitrary exclusions from treatment. Objection number two revolves around a recent attempt to provide contractual grounding for health maximisation based on choice under a Rawlsian veil of ignorance while a third issue deals with questions of causation that are excluded from all consequentialist approaches. Sometimes such exclusions are of debatable significance (e.g. cancer through smoking, discussed most recently by Persaud (1995)) but it will be shown that there are strong socio-demographic reasons why some elements of QALY differences should be eliminated from the determination of entitlements.

i) The arbitrary exclusion problem

Suppose society is divided into two mutually exclusive groups X and Y. Members of each group are affected by a disease (that could, but need not, be different for each group) which is fatal if not treated but otherwise completely treatable. All population members have the same life expectancy and differ only in terms of the age at which the disease strikes. Members of group X contract the disease with probability p_x ³ at age a_x . Corresponding facts hold for members of Y (see Table 1 below):

² The decision problem is one which currently faces district health authorities in the UK.

³ This is the conditional probability of contracting the disease, given membership of X.

TABLE 1
THE ARBITRARY EXCLUSION PROBLEM

	Group X	Group Y
Group Size	n_x	n_y
Proportion Affected	p_x	p_y
Age at which disease strikes	a_x	a_y

Treatment for everyone costs one unit and is funded from a health care budget size B . The budget is sufficiently constrained that it would not be possible to treat all patients in either group, i.e. $B < \text{Min}(n_x p_x, n_y p_y)$. This simple⁴ but quite general account of the rationing problem helps us ask how the health care budget should be spent.

Health care maximisation makes a clear prescription and gives treatment to all those in the group where the disease strikes first, since a greater number of (quality adjusted) life years are generated. Whilst in principle those who hold deep health maximisation intuitions must favour such a choice even where $|a_x - a_y|$ is small, perhaps only one year, it could be argued that in practice individuals may exhibit indifference between the groups for cognitive reasons⁵.

However, where the affliction ages are wider, but still small, it seems reasonable to assume that health maximisation may be deemed unfair because members of one group (all 41 year olds for example) end up being excluded from treatment for reasons which seem somewhat arbitrary (40 year olds have priority). Even many of the '40 year olds' might feel that a small age difference (hence a QALY difference) is not sufficient to entirely exclude one group from the opportunity of treatment, particularly in the extreme where treatment may be a matter of life and death. It is perfectly true that if a member of the 41 year old group struck had been a member of the 40 year old group, health maximisation would have preferred them so there is a sense in which health maximisation does provide equality of opportunity⁶. However it is an equality that depends on the truth of a counterfactual which seems only artificially relevant. For many people, the fair solution is one that gives an equal opportunity of treatment to those who are in need. In this case, that means the set of affected individuals who are in either category. People with these intuitions do not accept that being five years older is enough to exclude a person from being considered for treatment.

Those who hold that health maximisation is not appealing do not need to commit themselves to saying that the QALY measure is irrelevant in all rationing decisions where age plays a role but just that they reject the decision rule in which QALYs are counted equally regardless of where they are produced.

⁴ An important feature of the example is that it frames the allocation decision as one in which group entitlements are set. Sometimes decision problems at the level of individual choice are adequate but the group setting is strictly a more accurate level of rationing at this level.

⁵ We thank an anonymous referee for this point.

⁶ Levin (1981) provides a useful discussion.

Without excluding other possibilities, one way to sum up objection to the health-maximisation position is to say full recovery and the restoration of a complete life, is of *equal value to each and every person treated* regardless of whether they happen to be 40 years old or 41 years old at the time they are treated. Furthermore, and this is the point, society wants to treat their entitlements to health care resources in a way that reflects this equality. Whilst it may be that utilitarianism in this situation would prescribe equal priority to both groups this is not necessarily the case and it is not therefore clear if health maximisation and utilitarianism stand, or fall, together. Shifting treatment between groups may increase the amount of ‘good’ done, to borrow the language from John Broome’s (1993) recent project, for example by gaining economically productive years. Given this interpretation utilitarianism would advocate treating the younger group as would health maximisation.

One method of allocating resources that reflects equality of entitlements is to create a pool of potential patients, size $n_x p_x + n_y p_y$ and to randomly select from within the pool until the budget constraint is satisfied. Each person in need would have a probability of being treated equal to $B/(n_x p_x + n_y p_y)$ irrespective of who they were (which group they belonged to). There are other possibilities: one might think the fair thing to do is to allocate resources equally between the groups and then to randomly select within each group. In this case, the probabilities of being treated conditional on being in need are $B/2n_x p_x$ and $B/2n_y p_y$. This proposal may, however, be less appealing than the first one: it could mean that members of a very large group are virtually excluded from access to treatment compared, say, with members of small groups and we shall return to the interpretation of such issues in section 2.

ii) Rational Egoism and the Problem of Uncertainty

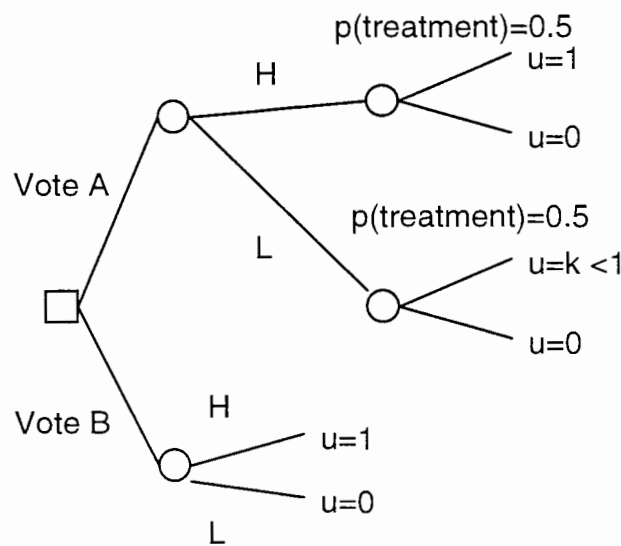
The Rawlsian veil of ignorance is a technique much discussed in philosophy, economics and medical ethics, to assess justice in social institutions. This theory suggests that the course of action undertaken by rational egoists from the hypothetical position of not knowing their own position in society may be deemed just both in procedural and distributive terms.

Singer et al (1995) support the cause of health maximisation using a veil of ignorance argument. Two examples are given to illustrate their case but we choose to concentrate on the second of these as the first deals with the concept of a ‘stronger interest in continuing to live’ which, in addition to being of questionable coherence, is compatible with utilitarianism rather than health maximisation⁷. The problem they discuss is one in which two rational egoists must agree principles for allocating health care where both are in need of a heart transplant without which they will quickly die. However, one has a lower quality of life score due to a physical condition unrelated to the heart problem (this is not sufficient to give a negative quality of life i.e. the individual still wants to go on living). In addition, we also assume (for sake of explicitness) that both individuals choose principles they would wish to prevail at the time the decision has to be made ie that they are dynamically consistent.

⁷ We believe, however, that similar comments could be made about both examples.

From behind the veil of ignorance agents must decide between two positions. Position A is one in which there is a 50:50 chance of receiving the treatment and therefore living, regardless of your quality of life (H=High, L=Low). Position B is one in which you are treated and live with certainty (conditional on having the higher quality of life) or you die. According to Singer *et al.* (op cit.) voting for position B, consistent with QALY maximisation, will be chosen by the rational egoist since this gives an equal probability of dying as position A but if s/he lives it will be with a better quality of life. Our rebuttal of this their argument depends on a claim similar to that levelled by Harsanyi in his critique of Rawls⁸. For clarity the situation is summarised in figure 1.

Figure 1: Decision Tree for Rational Egoist in the Singer et al Problem



After voting for A or B, nature determines first whether you are the high quality of life generator, and then, if you voted for A, whether you should be treated with a 0.5 probability. Qaly-maximisation allocates treatment to the person capable of generating more utility and Singer et al claim this is what a rational egoist must choose. However at the decision node, a vote for B involves a choice of the outcome (utility) set $\{1, 0\}$ over the set $\{1, k, 0\}$. The choices are in fact *equivalent* under either maximin or maximax. If we apply insufficient reason and treat H and L as equally probable, the expected utility of B is 0.5 while the expected utility of A is $0.25 + 0.25k$ which by the inequality on k is less than 0.5. This the result that Singer et al want but note that it depends on two assumptions which were implicit in their discussion of the setting: first they had to assume that the rational egoist must apply insufficient reason and secondly that k is less than one. Neither assumption is necessary. Insufficient reason is unacceptable as a foundation for probability and only one of many possible and reasonable attitudes to ignorance. Further is questionable to argue that the utility from recovery of a

⁸ We thank an anonymous referee for this insight. Harsanyi (op cit) is one of a number of people who argue that rational agents could be risk preferring or risk averse - a point perfectly compatible with the view that most people are risk averse in many everyday situations.

disabled person or someone who is unhappy is less than for anyone else. One could make the point that utilities are non-commensurable but one could also argue that the utility of full recovery for people whatever (almost) their physical or mental state, was the same. Singer et al's case seems to be one plausible possibility but necessity is far from proven.

iii) The Relevance of Causes

Health maximisation is blind to causes. It matters not why or how a patient generates additional QALYs, just that they do. By contrast, frameworks that make allowance for causes in their evaluations of states cannot be consequentialist as they go beyond values of the states. There is at present a debate about the extent to which people engaged in risky activities should be eligible for publicly financed health care. In France, mountaineers pay for their own rescue services (via insurance) whilst in the UK, part of such rescues is often provided by voluntary contributions of time and money. Those who believe that the extent to which a person is responsible for their medical needs should influence their access to publicly funded health care cannot be consequentialists and *a fortiori* cannot be advocates of health care maximisation.

Our point about causation, however, goes beyond issues to do with personal responsibility. Recently there has been discussion of the fact that QALY estimates of drug efficacy based on traditional clinical trials (conducted on non-representative samples) may lead to biased estimates of value compared with those based on prescribed drug use with, say, an older population Balthussen *et al* (1996). In some contexts, the point is one that must surely be taken into account. However, in entitlement decisions there are, we suggest, situations in which QALY differences *due* to socio-demographic variables should be factored out rather than in.

Consider, for example, a situation in which treatments for stress-related conditions have been ranked according to the average QALY for three groups, each with a distinct socio-demographic mix. All health-maximisers need to know about the nature of the groups is summarised in the QALY data. However, imagine that we find out that the groups respectively comprise mainly the following: well-off businessmen, women who work outside the home and who are bringing up young children, and men from a poor, ethnic group characterised by high levels of unemployment. Let us also assume that the quality improvements in people's lives from treatment are fairly similar as are the average ages of members in different groups but that QALY differences between groups exist mainly as a result of disparities in life expectancy between the groups. If the QALY ranking is businessmen first, working women with children second and poor minority group members third, then this is how health maximisers must prioritise the treatments that apply to each of these groups.

This is inappropriate. We know that life expectancy is positively correlated with socio-economic status but we do not expect entitlements to publicly funded health services to depend on this status, directly or otherwise⁹. If poor people suffer simply because the expected QALYs generated

⁹ The expectation is normative - in reality the relation is precisely what we would expect to find.

following successful treatment are less (the poor die younger), then there is no doubt that QALY differences *should* be ignored¹⁰.

On the other hand, it could be that expected benefits from treatment for the poor are lower, however, because they tend to lack the resources necessary to complete a course of treatment or adhere to a new set of behaviours. This is the case, for example, in the treatment of TB in developed countries. This seems to be an area where it is harder to say that the QALY difference should not be taken into account in determining entitlements. As we shall note later, one area where doctors are willing to be somewhat more explicit about rationing at the patient level is where the probability of successful treatment is low.

III. ALTERNATIVES TO CONSEQUENTIALISM

In addition to the value we place on health, we may wish health-care entitlements to reflect a variety of non-consequentialist values. Here we want to suggest that objections to health maximisation (or to utilitarianism for that matter) draw support from four main sources: rights, social contracts, voice and community values. In our discussion of these sources, it should be remembered that we are advocating they be integrated into a rationing scheme that depends also on consequences.

i) Rights

The language of rights closely corresponds to rationing decisions as they are debated and, whilst such discussion may be of little use alone (no individual has a right to any specific health treatment regardless of cost) we suggest that there is a useful link with consequences beyond the instrumental nature of some rights. As Sen's theory of capability rights suggests, measures such as the QALY and options for different groups may be used to monitor rights violations rather than pursuing health maximisation.

ii) Promises/Actual Social Contracts

Many people, particularly the elderly, have paid national insurance contributions in the belief that 'cradle to grave' care would be provided by the NHS. We believe that such agreements, although somewhat implicit, may be regarded as paid for entitlements that should restrict age-based rationing.

iii) Votes/Public Opinion

Procedural as well as substantive rights are relevant to health care rationing, and voice is one of the most important elements of procedural preferences, Lind and Tyler (1988). Whilst organisations require public support if they are to perform their functions, not only may this lead to a conflict with health maximisation but may also result in excluding minority groups from treatments.

¹⁰ In a sense our argument is a relation to Harris's (1987) discussion of priority setting with the disabled and might be seen as an extension of his critique of health maximisation.

iv) Communitarianism

Communitarians emphasise the importance of exchange between individuals and the local communities to which they belong. Individuals have duties to their communities, (which might well extend to minimising activities like smoking that might impose unnecessary costs on their communities), while at the same time communities value family units and act to preserve their structure. The health of the elderly, for instance, may be given a priority which is not sufficiently reflected in the QALYs they generate.

v) Theoretical overview.

Drawing these issues together we argue that any normative rationing guidelines must integrate several things, the main items being: consequences, rights, votes, actual social contracts (promises). Health maximisation deals only with one of these frameworks. For empirical purposes, it is also important to factor out variables that may play a role in determining entitlements whether they are of normative significance or not - lobbying and the opinion of medics are two such variables illustrated.

If one accepts that a rationing agency might not need to adopt one approach lock, stock and barrel, then the moral theories reviewed should not be regarded as competitors but rather as complementary parts of a framework that integrates different kinds of claims. There is growing survey evidence that health maximisation is only appealing in certain contexts. For instance, Nord *et al* (1995) in discussing some extremely important and valuable empirical results, nevertheless closely associates the empirical rejection of health maximisation with concern about the contribution an economic approach might make to rationing. Our conceptualisation of rationing as a synthetic task shows that the rejection of a *decision rule* like QALY maximisation is perfectly compatible with the use of *outcome measures* like the QALY.

We can also use this conceptualisation to track the actual development of normative frameworks over time. For example, the first ranking of treatments by Oregon State in 1990 was based only on an analysis of benefits and costs (consequences). However, forced a year later to produce a more 'intuitive approach' (Peters (1995 p502)), the Health Services Commission combined consequences with professional judgement and their own interpretation of community values. However, this too was rejected by the Federal Government on the grounds that it violated rights of the disabled. Though the charge was contested, a revised version of the plan dropped reference to quality of life and used a ranking based on mortality, with cost as a tie-break, and placed greater weight on preventive services in recognition of community preferences. The final version of the plan then reflects consequences (though not in the way health maximisation prescribes) and to a small extent votes and community values. It seems to be protected from direct lobbying influences but makes no explicit allowance for any previous social contracts or health expertise. Whilst our analysis supports the integration on non-consequentialist issues, there is nothing in it to recommend the wholesale eradication of quality of life issues. One can argue that discussion of what relative weight should be given to votes over consequences, has no analytical solution. In this sense, the communitarian concern with universal

doctrines seems right. In any case the pattern that emerges from the Oregon experiment is one in which a relatively simple, consequence based framework, is elaborated to incorporate normative sensitivities excluded by health maximisation.

IV. SURVEY METHODS AND RESULTS.

Health care entitlements, we have argued, should be functionally dependent on consequences, rights, votes, actual social contracts and community values. The decision rule of health maximisation focuses on just one of these which is why, so we contend, the doctrine seems so alien to many. In the following sections we test the validity of our criticisms of health maximisation and the level of support for alternative frameworks which we have advocated using a self administered, anonymous questionnaire. It identifies elements of frameworks that the public believe are important and that we believe should be integrated with health outcomes to form an acceptable health care rationing mechanism.

Our empirical results will relate to a number of the conceptual links between QALY maximisation, its problems, and the alternative frameworks we have discussed. First, we shall provide evidence relating to the problem of arbitrary exclusion and people's concern for equal treatment for those in equal need. Second, we shall provide evidence that shows many people believe that extending the health-care benefit to incorporate various utilities, as utilitarians would want, is inappropriate. Third, we provide evidence that indicates many people are sensitive to information about causes and duties, as non-consequentialist theories suggest might be appropriate. Fourth, we provide evidence that sheds light on the extent to which people believe health-care rationing is a social choice about which voted related information should be collected.

Specific framing issues are dealt with separately in subsequent sections but some general points about the survey design are appropriate here (see also footnote 17). Firstly, the survey was piloted using three variations of the questions before arriving at the final version. These pilots were used mainly to address individual question wording (see for instance Moser and Kalton (1971) and Dillon (1990)) but issues such as the order of questions and response rates were also examined¹¹. It was

¹¹ The questionnaire was designed to minimise a number of traditional methodological concerns. First we ensured that question words were as neutral in the description of options as possible. In some cases we used the phrase 'some people argue that...' so as to reduce any bias due to respondents' perceptions of what might be socially acceptable answers - though we note also that in many cases, because different welfare/moral theories prescribe different courses of action - all responses could be argued to be socially desirable. We also sought to describe options in as symmetrical a way as possible. Open form questions have been shown to elicit (Dillon op cit p118) more reports of socially embarrassing behaviour but we felt that this was not a major concern here and that the demands of quantitative analysis more than justified our use of closed form questions. We included 'don't know' and equal preference response options where-ever possible as we did not want to force a preference where none existed. Introduction of 'don't know' options has been shown to reduce agreement with other substantive options but we found that very few respondents checked this item when given the option. In their discussion of solutions to posed by surveys of opinions, Moser and Kalton (op cit) identify two kinds of responses: the first tries to estimate (and put bounds on etc) the proportion of a population who agree with a particular opinion survey whilst the second asks individuals a series of questions in order to provide a measurement of attitudes. As our empirical analysis is driven by the theory of QALY maximisation, and as it contains information that it relates the sample closely to the adult citizenry, our work illustrates the former

decided that none of the questions should mention costs directly but control for this by making it clear that potential patients differ only in terms of the criteria mentioned in the situation descriptions. This approach was decided on in order to avoid overly complex descriptions whilst still controlling for this obviously crucial component in decision making.

The final version of the survey was sent out to a sample of Leicestershire residents drawn from the electoral register. This was considered the most reliable and up to date sampling frame with postal addresses available. A usable response rate of 31% was achieved ($n=144$). A covering letter was also sent which introduced the concept of rationing/priority setting. As a result of feedback from the pilot surveys it also explicitly stated that the study was not related to the level of funding for the National Health Service. In addition to this respondents were asked for a small number of socio-economic details. Exact, binomial confidence intervals (C.I.s) are reported where appropriate, Armitage and Berry (1994).

See appendix 1 for socioeconomic characteristics of respondents.

Prioritisation issues.

i) QALY maximisation and arbitrary exclusion

In this section of the survey we test the extent to which respondents agree with QALY maximisation as a rationing device by using age differences between groups of patients as a proxy for health gain. Whilst there is existing evidence to suggest that there is little support for rationing by age¹², questions here explicitly test health maximisation by controlling for factors such as prognosis after treatment.

Respondents were asked to consider how funds should be allocated between two kinds of disease if it were not possible to treat all those affected when patients differ only in age. Whilst uncertainty may be characteristic of medical decision making in practice it was decided to abstract away from this for reasons of simplicity. QALY issues were further exaggerated in the decision problem by equating treatment with full recovery, including normal life expectancy, and lack of treatment with death. Four options were presented.

'QALYMAX' (QALY maximisation) is where all resources are used to treat those in the lower age group first with those in the older group receiving treatment only if there are funds left over.

'FAVYOUNG' entails allocating more resources to the treatment of the disease which affects the younger group. It does give a degree of preference to the younger group and consequently does reflect a concern for health outcomes but does not necessitate the complete exclusion of a patient group from health care entitlements on grounds of age, which may be seen as somewhat arbitrary, as would occur with a health maximising approach.

strategy. However, the fact that most people seem to believe that patients should be given equal priority with some diminution of the effect when age differences are very large indicates evidence of a particular attitude also.

¹² See for example Nord et al. (1995) for survey work in Australia, Kuder (1993) for focus group evidence in USA. Bowling (1996) does include the topic of age in her survey work based in the UK but questions are not controlled in such a way that implications for QALY maximisation can be drawn.

'EQUAL' indicates the option of equal allocation of resources between the two diseases.

'DON'T KNOW' was also included for the undecided.

Initially respondents were asked to choose between groups where age differences were large (80 years versus 40 years). This differential was gradually reduced until groups differed by just one year (41 years versus 40 years). Results are shown in table four.

TABLE 4
QALY MAXIMISATION.

	MEAN	95% C.I.'s	QALYMAX		FAVYOUNG		EQUAL		DON'T KNOW	
			N	%	N	%	N	%	N	%
<i>Age Differentials (yrs.)</i>										
80 vs. 40	0.8357	0.7638-0.8929	23	16	27	18.8	90	62.5	4	2.8
70 vs. 40	0.8865	0.8223-0.9337	16	11.1	27	18.8	98	68.1	3	2.1
60 vs. 40	0.9650	0.9203-0.9886	5	3.5	15	10.4	123	85.4	1	0.7
50 vs. 40	0.9930	0.9617-0.9998	1	0.7	4	2.8	138	95.8	1	0.7
41 vs. 40	0.9930	0.9617-0.9998	1	0.7	0	0	142	98.6	1	0.7

Means and confidence intervals are based around a coding of QALYMAX = 0, alternatives=1.

Those concerned purely with health maximisation must choose option one in all situations, irrespective of the size of age differences. The decision problem was described such that even where the age differences may be small, failure to choose this option involves a deliberate sacrifice of QALYs. Results show that support for such an approach is limited. Even in the first scenario, where one would expect support for QALY maximisation to be strongest since the age difference between the two groups of patients is largest, 95% confidence intervals indicate that the proportion of those rejecting this approach ranges from 76% - 89%. Furthermore, as age differences are reduced the proportion of respondents not agreeing with QALYMAX increases. This reaches a maximum range of 96% - 100% at a ten year age gap. These figures indicate an overwhelming rejection of the health maximising approach. Respondents generally do not agree that age should be used as a rationing device even when there are large differences between groups and therefore large differences in potential life years saved (or lost). A similar pattern is found when examining the number of respondents opting for the intermediate FAVYOUNG option with a significant level of support (19%) where age differences are largest, falling to zero when ages differ by just one year.

Whilst these results indicate a rejection of the health maximising approach to rationing they should not be seen as a complete lack of concern over health outcomes, particularly when age differences are large. The sample mean, indicating the proportion of respondents rejecting any skewing

of resources based on age, is 0.6429 (95% C.I.s, 0.56-0.72) when the first group are aged 80 years old. Although sample means increase dramatically as the age of the first group of patients is reduced, responses indicate that the proportions of those indicating any concern for health outcomes is noteworthy.

ii) Limited appeal of forms of consequentialism

The decision rule of QALY maximisation is a variant of consequentialism since alternatives are judged only in terms of the health outcomes produced. There has been a tendency to use the term in a positive prescriptive sense despite the fact that there is not the philosophical tradition of argument for health maximisation as there is for utilitarianism, upon which traditional economic tools are based. This section tests four competing types of consequentialism that are derived from utilitarianism in that they widen concern away from the individuals health (which is the concern of QALY maximisation) towards a more utilitarian metric which would include the welfare of all actors affected by a medical procedure, rather than the individual patient.

Potential confounding influences were considered to be too numerous to include in the descriptions of the situations under consideration. However, despite the fact that pilot results indicated respondents were not influenced by perceptions of factors such as differential costs or expected treatment outcomes that would bias the results, included from the beginning of this section was the general statement that patients are similar in all aspects other than those specified. This served as a security measure against response bias without making the questions excessively repetitive or lengthening the survey. Results are shown in table five.

TABLE 5
VARIETIES OF CONSEQUENCES.

	Mean	95% C.I.s	Consequentialist		Anti-consequentialist		Egalitarian		Don't Know	
			N	%	N	%	N	%	N	%
<i>Types of outcome</i>										
Personal Utility	0.8810	0.8113-0.9318	15	10.4	n/a ¹		111	77.1	18	12.5
Spouse utility	0.9650	0.9203-0.9886	5	3.5	1	0.7	137	95.1	1	0.7
Family Utility	0.9301	0.8752-0.9660	10	6.9	2	1.4	131	91	1	0.7
Economic Utilitarianism	0.9859	0.9500-0.9983	2	1.4	14	9.7	126	88	2	1.4

¹ This option was not considered relevant to this question.

Mean and confidence intervals are for where responses that correlate with a maximising approach are coded as 0, alternatives are coded 1.

The first question in this section asks whether a broader measure of outcome than the health of an individual, personal utility, should be used in determining entitlements to health care. Results indicate a sample mean of the proportion of people disagreeing with personal utilitarianism of 0.88 (95% C.I., 0.81-0.93). Despite the magnitude of responses favouring equality of access for patients irrespective of the effect on personal utility, there is still a greater degree of support for this type of consequentialism than the other more inclusive types tested in this section.

The three other questions included in this section were concerned with consequences outside the individual sphere. Choices were offered between patients who differ only in marital status (Spouse utility), whether they have children (family utility), or income (economic utilitarianism). Options presented corresponded with a consequentialist ideology, an anti-consequentialist view, and an egalitarian view.

Firstly, when faced with a choice between a married and an unmarried person, the proportion of those who disagree with giving priority for treatment to the married person, as indicated by the sample mean, is 0.97 (95% C.I., 0.92-0.99), indicating an overwhelming rejection of this type of consequentialism. A second criticism of the health maximising approach to prioritising health services is that it does not incorporate the effects on a patient's dependants. Respondents were therefore presented with a choice between patients with and without children. A proportion of over 0.93 of respondents disagreed with the view that those with children should be given a higher priority than childless patients (95% C.I., 0.88-0.97), opposing the choice advocated by a consequentialist decision rule. Economic welfare was the broadest consequence respondents were asked to consider. In this question a choice between high and low wage patients was presented. In the absence of market failures, economic consequentialism advocates prioritising services for high wage earners yet our estimates show confidence intervals of the proportions rejecting this approach between 96% and 100%. Interestingly, the option to give priority to low wage earners received a significant degree of support (10%). Not only does this reinforce the strength of opinion against rationing by economic consequence but may also indicate that the concept of access to health services according to need should incorporate the ability to pay for such services privately.

Results in this section indicate that attempts to find a publicly acceptable rationing device based around a utilitarian philosophy are doomed to failure. Compared to results given where support for the QALY maximising approach is greatest (where age differences are largest) the maximisation rule receives a lower level of support when a broader range of consequences are considered. Subsequent sections of the survey test a number of alternative frameworks that may complement concerns for outcomes such as health gains.

iii) The Relevance of Causes.

Health maximisation focuses only on outcomes in terms of health. In common with all brands of consequentialism, it is blind to the underlying reasons for these outcomes. We focus here on the extent

to which health care entitlements are affected by how the need for treatment came to be generated. Questions are asked both in terms of specific conditions and with respect to risky behaviour in general.

In each of the scenarios presented we ask about priority setting between groups of patients suffering from the same condition such that the expected health gain from receiving treatment would, on aggregate, be the same for both groups. Results are shown in table six.

TABLE 6
THE IMPORTANCE OF RESPONSIBILITY AND CAUSE.

	Mean	95% C.I.'s	Relevant		Not relevant		Don't know	
			N	%	N	%	N	%
<i>Condition and Cause</i>								
HIV/AIDS: Illegal drugs vs. blood transfusions	0.5954	0.5062-0.6802	78	54	53	37	13	9
Lung cancer: Smokers vs. non-smokers	0.4706	0.3845-0.5580	64	44	72	50	8	6
Mountain rescue	0.8529	0.7821-0.9078	116	81	20	14	7	5
General disease: Risky lifestyle vs. caution	0.4031	0.3177-0.4930	52	37	77	54	13	9
			QALY max.		Anti-QALY max.		Equal	
Life expectancy: socio-economic group	1	1	0	0	12	8	130	92
Life expectancy: lifestyle	0.9236	0.8674-0.9613	11	8	6	4	127	88

Means and confidence intervals are calculated on the basis of health maximisation =0, alternatives =1.

Question one asks if priorities for treatment should differ between HIV positive persons who have become infected through the use of illegal intravenous drug use (and *may* be seen as responsible for their condition) and those infected through contaminated blood transfusions. Confidence intervals at the 95% level indicate that the proportion of those advocating preferential treatment for those infected through contaminated blood transfusions (and therefore rejecting a pure health maximising policy) ranges from 50% to 68%. A slightly lower proportion of respondents accept that cause is relevant in scenario two which presents choices between smokers and non-smokers requiring treatment for lung cancer. Confidence intervals in this situation indicate that the proportion of those choosing for non-smokers to receive a higher priority for treatment than smokers ranges from 38% to 56%. These results show that, in these specific situations, health maximisation is unpopular as it is blind to how health gains are generated.

Question three presents a similar situation in very general terms. Two groups of patients require medical treatment in a situation where there are insufficient funds to treat all those in need. One group require treatment as a result of engaging in risky behaviours whilst the other group are suffering as a result of events beyond their control. Respondents are asked to consider whether or not the cause of

disease is relevant to the priority for treatment that patients should receive. In this general situation there is a slightly higher level of agreement with viewpoint that patients in each group should receive an equal priority, as consistent with consequentialism. The proportion of respondents indicating that the cause of disease is relevant in this general case, as indicated by the sample mean, is 40% (95% C.I., 0.32-0.49).

In order to provide a comparison, question four frames the problem in an area outside the health service. Respondents were asked to consider whether mountaineers should be obliged to take out insurance to cover the costs of any rescue services they may require. This situation mirrors that faced in the health service but was included to identify differences in opinions between the NHS and other services supported by resources provided by a combination of public and voluntary sources. Results show that there is a far greater level of support for non equal access to such services than in the health sector. The sample mean of the proportion of the sample supporting compulsory insurance is 0.85 (95% C.I., 0.78-0.91).

Results in this section as a whole indicate that there is a moderate level of support for allocating priorities to patients on grounds other than expected health gains. Respondents are concerned with how health care needs are generated and are prepared to discriminate against those who fail to take precautions to protect their own health. The significance of this rejection of consequentialism, and therefore QALY maximisation, is particularly important given the framing of the questions. In each of the scenarios presented, equality of opportunity for patients equated to a health maximising viewpoint. Given what we know about attitudes to the NHS this meant that the questions were biased in favour of the health maximisation standpoint. This effect is apparent from the results gained in question four which show a greater level of rejection for the QALY maximising approach outside the immediate health service. Yet despite this results indicate a high level of support for cause relevance. Two supplementary questions in this section address this bias by framing the issue in an alternative manner. Both questions present a situation where two groups of patients are suffering from similar conditions but have differing life expectancies. In the first instance this is due to economic status, with those from a wealthy background enjoying a higher life expectancy. In the second case the patient group with lower life expectancies lead lifestyles that are generally considered to be risky for health. In each of these scenarios, QALY maximisation advocates allocating priority to the group with the higher life expectancy. Results however, show an overwhelming rejection of the QALY approach. Not one respondent opted to allocate a lower priority to the lower income group in order to generate greater health gains, with the majority opting for equal treatment of both groups. There were however, a small proportion (8%) who expressed a preference for the opposite view, that is, to give a higher priority to the low income group.

Similarly, in the second question in this section, there is little evidence of a willingness to adhere to the position advocated by the health maximising approach when this entails giving priority to a group of patients with healthy lifestyles. 95% C.I.s indicate that the proportion of persons holding a view that contradicts QALY maximisation is in a range from 87% to 96%.

Overall a strong rejection of the QALY maximising approach has been demonstrated. Whilst these questions cannot isolate the reasons for this rejection, it seems reasonable to suggest that this is due to concern with the way in which expected health gains are generated. The most likely confounding factor in this section is the egalitarian nature of public attitudes to the NHS which has been addressed both by including a scenario dealing with a similar issue outwith the NHS and by equating QALY maximisation variously with equality and inequality of access.

iv) Votes/public opinion

TABLE 7
VOTER OPINION

	Mean	95% C.I.'s	Strongly agree		Agree		Neutral		Disagree		Strongly disagree	
			N	%	N	%	N	%	N	%	N	%
<i>Role of consultation</i>												
Consultation exercises	2.4406	2.2688-2.6123	25	7	58	40	38	26	16	11	6	4
Surveys of voters	2.4861	2.3075-2.6647	26	18	55	38	37	26	19	13	7	5
Private insurance mirror	3.3287	3.1556-3.5017	6	4	27	19	41	28	52	36	17	12

Means and confidence intervals are based on strongly agree = 1,....., strongly disagree = 5.

Table seven shows responses to questions concerning citizens procedural rights in health care. Respondents were asked to consider the extent of their agreement/disagreement with three types of consultation process. The first two of these refer to methods of measuring public opinion, namely public consultations such as citizens juries, and voter surveys. The third question asked if health services should aim to mirror a private insurance based system as traditionally advocated by economist on the grounds that this is the most effective method of representing individual preferences.

Results show that there is general support for both forms of public consultation with point estimates around 2.4 (95% C.I., 2.3-2.6), where 3 is equal to neutrality and lower numbers represent agreement. This indicates that there is general support for health authorities involving the public in rationing decisions and that the form of consultation does not significantly alter the level of this support. Average opinion is slightly against distributing resources in a similar manner to private markets, with results indicating a point estimate of 3.3 (95% C.I., 3.2-3.5).

TABLE 8
VOTING AND RIGHTS.

	Mean	95% C.I.s	Health max.		Public opinion		Don't know	
			N	%	N	%	N	%
<i>Reason for difference</i>								
Minority population	0.1318	0.0787-0.2026	112	78	17	12	15	10
Popular treatment	0.5897	0.4950-0.6798	48	33	69	48	27	19

Table eight shows results relating to two questions which ask respondents to consider how health priorities should be decided when there is a conflict between health maximisation, voter opinions and the rights of individual patients. We are concerned here with the identification of rights based entitlements to health care without necessarily involving a trade-off with health outcomes and indeed, as previously suggested, it may be possible to judge outcomes in terms of their rights based implications.

The first of these questions presents a situation where a health authority must decide on the priority for a disease which affects only members of an ethnic minority group, meaning that there are relatively few voters advocating a high priority for this condition since they are unlikely to be at risk. The question does not directly specify the efficiency of available treatments since pilot studies revealed that this did not influence responses and only complicated the question. There are no grounds for rejecting treatment provision on health maximisation grounds. 95% confidence intervals indicate that the proportion of those who think the health authority should respond to public opinion and give this condition a low priority ranges from 8%-20%. There is therefore general agreement with the option supported on health maximisation grounds, although we suggest a rights based argument below for these responses.

The second section presents an alternative decision problem in which voter opinion is in direct conflict with clinical opinion. Respondents are asked to consider whether a health authority should provide a treatment which has a very low expected health gain and is therefore not supported by doctors, but which the public have said should be provided. In this scenario, results illustrate a much higher tendency for respondents to disagree with health maximisation with confidence intervals range between the 50% and 68 % levels.

The difference between the results gained in these two questions yield important implications for the importance of rights in the rationing debate. It is clear that health maximisation and voting alone, cannot explain these results. Our suggestion is grounded in health care rights. Firstly, broad support for a rights maintenance approach to rationing is exhibited. Respondents are generally willing to reject the option favoured by voters in question one when this would entail the violation of the rights of a specific group (an ethnic minority). This trend is reversed in the second question where there is a much higher level of agreement with voter opinion rather than health maximisation since the former option entails the provision of the service. Secondly, we argue that the results suggest a possible judgement of outcomes in terms of their implications for group rights. Question one in particular is

demonstrative of Sen's theory of capability rights where the outcome of providing treatment may reflect concerns for equality of access for different groups, specifically ethnic minorities, rather than a concern with health maximisation as a value in itself.

V. CONCLUDING REMARKS

The paper provides arguments for, and supporting evidence of, deeply non-utilitarian preferences in a real and substantive social choice problem. In doing so, it also helps illustrate the practical importance of theoretical concerns about welfare economics articulated by Sen and others. The inability of adults to produce expected health gains, even at the age of 80, has for many voters surveyed, no impact on entitlements. On the other hand, we find evidence, in the aggregate, that entitlements are a function of age so it would seem that any approximately true positive theory of normative judgements must be capable of integrating consequential and deontological considerations.

Our sample provides evidence of a strong desire to treat people equally regardless of age but not to use the health-care system as a way of compensating for socio-economic deprivations. We suspect that both mental accounting and equality issues may be playing a role in these results. The tendency to compartmentalise could reflect a desire to simplify but it might also reflect normative beliefs which insist that individuals, rather than the health outcomes they produce, be treated equally. Whether on further reflection and perhaps on the basis of some informed debate¹³, our respondents would still hold these normative views we cannot say though in further developments of the work we should like to explore methodologies that allow such distinctions to be made.

Sen's theory of capability rights is the only theory currently discussed by economists which performs the integration task mentioned above, yet our evidence draws attention to two further considerations. The importance of being able to formulate rights is now well understood - even if their formulation is, itself, debatable. Communitarians, however, have emphasised the importance of duties and our evidence shows that people do indeed attribute significance to duties in determining health-care entitlements and that the onus on the individual varies considerably depending on the issue involved. Finally, we have added to the growing evidence that issues of procedural fairness, particularly rights to representation and consultation, are of importance in economic decision-making. For many voters, such issues are more important than trying to produce results which mimic the outcome of a market process, though the approach is fundamental to the economic analysis of public sector provision. Our evidence suggests that in the allocation of commodities by the public sector, outcomes matter, but so do rights, duties and beliefs about due process.

¹³ Sen (1985) calls this the reflection test of rational choice.

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Appendix 1.
SOCIO-ECONOMIC DETAILS OF SAMPLE

	Male		Female		Total		GHS
	N	(%)	N	(%)	N	(%)	¹⁴
<i>A. Age (yrs)</i>							
<18	0	0	2	1.4	2	1.4	3
18-25	5	3.5	12	8.3	17	11.8	10.8
26-45	23	16	14	9.7	37	25.7	38
46-64	25	17.4	31	21.5	56	38.9	27
>65	18	12.5	14	9.7	32	22.2	19.9
<i>B. Gross Household Income (£'s per annum)</i>							
< 5000	12	8.3	23	16	35	24.3	18.8
5000 - 16000	30	20.8	31	21.5	61	42.4	37.9
16000 - 25000	15	10.4	13	9	28	19.4	19.6
> 25000	10	6.9	4	2.8	14	9.7	23.6
<i>C. Occupation</i>							
Employed	37	25.7	32	22.2	69	47.9	55.5
Self Employed	3	2.1	0	0	4	2.8	7.4
Unemployed	7	4.9	6	4.2	13	9	6.4
Retired	22	15.3	22	15.3	44	30.6	22.0
Other e.g. student, housewife	2	1.4	12	8.3	14	9.7	14.7
<i>D. Vote in 1997 election</i>							
Conservative	5	3.5	11	7.6	16	11.1	16.1
Labour	47	32.6	35	24.3	82	57	46.3
Liberal	9	6.3	6	4.2	15	10.4	7.7
Other	0	0	1	0.7	1	0.7	-
<i>Total</i>	71	49.3	73	50.7	144	100	

¹⁴ Figures for age, income and occupation are taken from the General Household Survey of 1994/95. (n=18237).

Voting behaviour taken from 1997 general election results, Leicester wards.