MONASH University
Business and Economics

Centre for Health Economics

Neglected Equity Issues in Cost Effectiveness Analysis – Part 2:

Direct and Indirect Costs, the Preservation of Hope, the Rule of Rescue, Patient Adaptation, and the *Ex Ante/Ex Post* Distinction

Dr John McKie

Research Fellow, Centre for Health Economics,
Monash University

Professor Jeff Richardson

Foundation Director, Centre for Health Economics,
Monash University

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LIST OF ABBREVIATIONS

BOD	burden of disease
CA	conjoint analysis
CEA	cost-effectiveness analysis
CUA	cost-utility analysis
DALY	disability-adjusted life year
EUT	expected utility theory
HRQoL	health-related quality of life
NICU	neo-natal intensive care unit
PTO	person trade-off
PYLL	potential years of life lost
QoL	quality of life
QALY	quality-adjusted life year
RR	rule of rescue
RS	rating scale
STTO	social time trade-off
SG	standard gamble
SWTP	social willingness to pay
TTO	time trade-off
VAS	visual analogue scale
WHO	World Health Organization
WTP	willingness to pay

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Neglected Equity Issues in Cost Effectiveness Analysis – Part 2

INTRODUCTION

This document continues the survey of empirical studies of social preferences for the distribution of health and health care begun in *Neglected Equity Issues in Cost-effectiveness Analysis – Part 1*. The two documents divide the empirical studies into three categories. Category A comprises two issues for which the evidence concerning the preferences of the public in Australia, and elsewhere, is persuasive and growing: severity of pre-treatment condition and realisation of potential for health. Category B comprises two issues for which the empirical evidence is suggestive but inconclusive: concentration and dispersion of individual health benefits and age. Category C comprises several issues for which the evidence concerning community preferences is at present only weak: high-cost illnesses, indirect costs and benefits, the preservation of hope, the Rule of Rescue, adaptation to illness and disability, and the *ex ante/ex post* distinction. It also looks at some corroborating evidence from experimental game theory concerning the importance of fairness in the allocation of resources. Categories A and B are included in *Neglected Equity Issues in Cost-effectiveness Analysis – Part 1*. The present document examines the issues in category C.

For all of the issues in this latter category the evidence that presently exists, which in some cases is scant, indicates a divergence between community values and those assumed in health economic evaluations. However, more studies are needed that attempt to quantify the social preferences involved before we can be confident that these factors should play a role in the economic evaluation of health programmes and services.

CATEGORY C

HIGH-COST ILLNESSES

Studies in Australia and Spain provide suggestive evidence that the populations in those countries reject the usual treatment of cost in economic evaluations (see Table 1). It seems that people reject, as a general criterion of economic policy, the non-provision of cost-ineffective services (Nord, Richardson et al. 1995b; Abellan-Perpiñán and Prades 1999). As discussed by Nord, Richardson et al., this is not necessarily perverse (Nord, Richardson et al. 1995b, p. 90). Allocative (but not productive) efficiency re-distributes resources between patients, and the evidence suggests that the public is reluctant to discriminate against patients who are unfortunate enough to have high-cost, or simply cost-ineffective, illnesses.

Table 1. Studies of Social Preferences Concerning Direct Costs

Study	Country	Number of Subjects	Type of Subjects	Elicitation Method
(Nord, Richardson et al. 1995b)	Australia	551	GenPop[a]	DCM[b]/SWTP[c]
(Abelson, Lomas et al. 1995)	Canada	280	GenPop/Health Officials	DelPol[d]
(Abellan-Perpiñán and Prades 1999)	Spain	149	Undergraduates	SWTP

    a   GenPop = General Population
    b   DCM = Discrete Choice Method
    c   SWTP = Social Willingness to Pay
    d   DelPol = Deliberative Polling

Individuals surveyed in Australia in 1995 decisively rejected the proposition that health services should be provided on the basis of least cost, because "people cannot be blamed for getting high-cost illnesses," because "severity of illness should count rather than cost," because people are "equally entitled to treatment irrespective of cost" (Nord, Richardson et al. 1995b, p. 85). Respondents continued to reject cost as an important criterion for assigning priority when interviewers were instructed to clearly point out the implications of this in terms of the number of people who could be treated, when it was pointed out that this would reduce subjects' own chances of receiving treatment should they fall ill, and when subjects were asked to allocate a budget between two groups of ill patients that made the opportunity-costs of different decision-rules transparently clear. In stage 1 of the study, which used a self-administered questionnaire, subjects were asked to choose between the following (Nord, Richardson et al. 1995b, p. 84):

1. Among patients who are equally ill, those who can be helped at low cost should have priority over those who can be helped at high cost, because this will allow more people to be helped when money is limited.

2. It is unfair to discriminate against those who happen to have high-cost illness. Priority should therefore not depend on the cost of treatment (except in cases where costs are extremely high).

The results showed that 81.4 per cent of respondents chose the equal priority option (2), while 18.6 chose to give priority to the least costly patients (1). Moreover, of those who rejected cost as a criterion for assigning priority, the greatest percentage (56.2 per cent) found the choice "not

difficult", whereas of those who chose to give priority to the least costly patients, the greatest percentage (39.6 per cent) found the choice "very difficult".

Follow-up interviews in stage 2 of the study confirmed these findings, with a slight decrease in the percentage rejecting cost as a criterion for assigning priority (78 per cent in stage 2). One group of subjects was given a slightly re-worded version of option (1), which replaced the words "should have priority" with the weaker "should have some priority". A clear majority of 70 per cent still chose option (2). When it was pointed out that treating high-cost patients would reduce their own chances of receiving treatment should they fall ill, no one changed their mind. Finally, when asked to allocate a budget between two illnesses, 94 per cent preferred to allocate the budget in a way that did not maximise the number of patients who would be treated. According to Nord, Richardson and colleagues, the results suggest that "the concern with allocative efficiency, as usually envisaged by the economists, is not shared by the general public and that the cost-effectiveness approach to assigning priorities in health care may be imposing an excessively simple value system upon resource allocation decision-making" (Nord, Richardson et al. 1995b, p. 79).

In a Spanish study by Abellan-Perpiñán and Prades (see *Neglected Equity Issues in Cost-effectiveness Analysis – Part 1*), subjects were asked to allocate a budget between two patients, John and Andrew (Abellan-Perpiñán and Prades 1999). It would cost one million pesetas to produce a year of life for John and two million pesetas to produce a year of life for Andrew. When asked how they would split the money, 74 per cent chose to ensure both patients would gain 16.6 years, although this meant spending twice as much on Andrew (33.3 million pesetas) as on John (16.6 million pesetas). Only 4 per cent of respondents were willing to spend more money on John than on Andrew, even though this was the most cost-effective alternative. When the same subjects were asked to imagine that Andrew would live the rest of his life undergoing dialysis, 84 per cent did not change their view. In a separate exercise (Group 2), subjects were told from the beginning that Andrew would live the rest of his life undergoing dialysis. In this case only 29 per cent chose to ensure that both Andrew and John would gain 16.6 years (by allocating 33.3 million pesetas to Andrew and 16.6 million pesetas to John). However, the support for health maximisation was still weak, with only 27 per cent of subjects being prepared to spend more on John than on Andrew, despite the fact that this was the most cost-effective alternative.

Further evidence on the relative unimportance of direct costs was detected in a Canadian study by Abelson, Lomas et al. Participants were asked to rank the following in terms of their importance for health-care and social-service decision making: needs, benefits, costs, preferences (Abelson, Lomas et al. 1995). Five different groups took part in the study: randomly selected citizens, attendees at town-hall meetings, appointees to district health councils, elected officials and experts in health care and social services. Costs were rated third in importance by all groups except the elected officials, who placed it second. All five groups thought that information about needs was most important, with benefits being rated second by all groups except the elected officials. Information about preferences was placed last by all groups.

INDIRECT COSTS AND BENEFITS

Controversy exists about whether indirect costs and benefits should be included in economic evaluations of health services and programmes, if so which ones, and how they should be measured (Koopmanschap, Rutten et al. 1995; van Roijen, Koopmanschap et al. 1995; Johannesson and Karlsson 1997; Weinstein, Siegel et al. 1997; Liljas 1998). Indirect benefits to society from health care include the early return to work of patients, or their retention in the workforce when they would have otherwise died. They are "the production gains to society

because more people are well, or alive, and able to return to work" (Torrance 1986, p. 2). Indirect costs include the production lost while patients undergo treatment, reduced productivity at work, the recruitment and training of replacement personnel, and so on. They are "the non-health care costs which accompany the treatment" (Olsen and Richardson 1999, p. 18). It has generally been accepted that indirect benefits and costs should be included in the comparison of the overall costs and benefits of a programme. In the case of indirect costs Johannesson and O'Conor state: "To provide a theoretical foundation and a rationale for using cost-utility analysis, a first step seems to be to include all the costs in the analysis rather than only health care costs" (Johannesson and O'Conor 1997, p. 244). The Canadian guidelines on economic evaluation of pharmaceuticals also endorse the inclusion of indirect costs (Canadian Coordinating Office for Health Technology Assessment 1994).

However, the inclusion of indirect costs and benefits is likely to advantage some groups and disadvantage others in ways that raise questions about fairness. For example, the inclusion of indirect benefits is likely to favour working people, especially those with high incomes with whom are associated the largest production gains and losses, and disadvantage the elderly, the long-term unemployed, the chronically ill and the permanently disabled. Moreover, high-income individuals are themselves the chief beneficiaries of their own high income, which raises in pointed form the question whether it is fair to include indirect benefits in economic evaluations. No less disturbingly, the inclusion of indirect costs and benefits without constraints may result in de facto sexual and racial discrimination, to the extent that income and wealth are correlated with sex and race (Caplan 1987; Ferrans 1987; Ogden 1987; Held, Pauly et al. 1988; Turenne, Held et al. 1996). By contrast, if health care is allocated on the basis of "equal access for equal need" (Mooney 1991; Olsen and Rogers 1991), for example, there would seem to be little justification for the inclusion of indirect costs and benefits, except to the extent that they bear on access or need. In contrast to Canada, the Australian guidelines on economic evaluation of pharmaceuticals oppose the inclusion of indirect costs (Commonwealth of Australia 1995).

There are two main ways of calculating production gains and losses. The human capital approach uses gross earnings as a proxy for the value of a person's output (Weisbrod 1961a; Weisbrod 1961b). The value of the production gain to society of a person's return to work at age 35, for example, is taken to be that individual's total earnings from age 35 until retirement. Van Roijen, Koopmanschap and colleagues used this method to compare the indirect costs of diseases in the Netherlands, Sweden and the United States (van Roijen, Koopmanschap et al. 1995). However, this method tends to exaggerate production losses to society, since it takes no account of the fact that absences from work due to illness and death can be filled by the unemployed or covered by other employees. Taking account of this, the friction cost method limits production losses to the period of time needed to replace a sick, injured or dead worker, which depends on the labour market (Koopmanschap, Rutten et al. 1995; Koopmanschap and Rutten 1997). Controversy exists about whether production gains and losses should be calculated using the human capital approach or the friction cost method.

Whichever approach is adopted, the main argument for including indirect costs and benefits was summed up by van Roijen, Koopmanschap et al: "production losses due to illness and production gains due to health care influences the wealth of society and should therefore be incorporated in economic evaluations of health care programmes" (van Roijen, Koopmanschap et al. 1995, p. 16). Indirect costs and benefits are no less real for being indirect, are often substantial compared with direct costs and benefits, and clearly influence the scarcity of resources. Arguably, therefore, they should be included in economic evaluations of health programmes and services. If not, the argument runs, one programme or service may be ranked higher than another only because certain consequences are being ignored.

However, it is not obvious that all indirect costs and benefits should be included in economic evaluations of health programmes and services, despite the consequences of not doing so. As Brock points out, "there may be good reasons why specific consequences should not be counted when we make particular assessments of outcomes" (Brock 2003). For example, as previously noted, programmes and services that enable productive people to return to work will have higher priority if indirect benefits are included, while programmes that improve the health of people who do not contribute to society's aggregate production will accordingly have lower priority, and it is debatable whether this should influence the allocation of health care. Note that this effect might be minimised, but not eliminated, by ascribing an implicit wage rate to unpaid productive persons (such as unpaid home-makers). In brief, excluding indirect costs and benefits may involve ignoring certain consequences, but ignoring certain consequences may be appropriate for equity reasons in a given context.

In recognition of this, Olsen and Richardson suggest the possibility of viewing some benefits of health care as "socially irrelevant", a class that would include, for instance, the net benefits of crime. They argue that it is for society to decide which indirect benefits are relevant in different contexts – that is, which benefits are "socially relevant" and which ones are not. There are several ways of restricting the class of "potentially relevant production gains" from health care (Olsen and Richardson 1999, p. 21). First, they might be restricted to those that have an impact on the rest of society. That is, the utility arising from a patient's own consumption would be ignored, since this is based on income (Weinstein, Siegel et al. 1997). Second, they might be restricted to those that lead to more health care, rather than public goods that do not affect health. This is one form of the "separate spheres" argument (Walzer 1983; Kamm 1993; Brock 2003). Third, only a patient's taxes might be included, as these benefit others. But even with these restrictions in place conventional economic analyses will favour high-income earners, since such individuals will contribute more in tax and therefore contribute more to health care. If it is considered unfair that high-income earners should receive priority access to publicly funded health care, this would suggest the need for an equity-efficiency trade-off. The optimal situation may lie somewhere between maximising the total health in society and distributing health gains equitably. There is, however, little information about such social preferences for the inclusion of indirect benefits in economic evaluations.

In one of the few studies of indirect costs in the health context, Nord, Richardson et al. asked a random sample of Australians whether (1) working people and non-working people should have equal priority when they have the same illness, or whether (2) people in the workforce should have some priority over non-working people, in order to limit possible economic losses to the country (Nord, Richardson et al. 1995b). The results of this mail survey showed that 87 per cent of respondents rejected participation in the workforce as an important criterion for assigning priority. Moreover, 79 per cent found the decision "not difficult" and 13 per cent had only "slight difficulty" making the choice. Follow-up interviews in stage 2 of the study confirmed these findings, with a slight increase in the percentage rejecting workforce participation as a criterion for assigning priority. This suggests that the usual inclusion of indirect costs and benefits in evaluations of health services may not be in keeping with community values.

Neuberger, Adams and colleagues surveyed the general public, family doctors and gastroenterologists in the UK on which factors should be used to select patients for liver transplantation (Neuberger, Adams et al. 1998). Subjects were asked to select four of the following criteria: time on waiting list; age; value to society, alcohol consumption; work status; outcome; drugs. Of the gastroenterologists, 77 per cent included work status ("those who are likely to return to paid work or caring for family after transplant") among their chosen four criteria. For this group, work status was second only to outcome in order of importance. Of the family

doctors, 57 per cent chose work status, and only 44 per cent of the general public chose this criterion. "Value to society" was selected by 31 per cent of family doctors and gastroenterologists, whereas 21 per cent of the general public chose this criterion. This suggests that the general public places much less emphasis upon indirect costs and benefits than the medical profession.

Table 2. Percentage of population Registering Choices

Person Y	Person Z	Easy Y	Diff Y	No Choice	Diff Z	Easy Z
Unemployed	Employed	2.9	12.7	50.2	25.7	7.4
Unskilled	Director	8.9	19.6	49.9	16.8	4.7
Lorry Driver	Teacher	4.8	10.4	50.3	27.3	7.2

Source: (Charny, Lewis et al. 1989)

Charny, Lewis et al. surveyed 719 subjects in Cardiff on their attitudes towards priorities in allocating life saving treatment. Among other things, respondents were asked to make a choice between saving the life of an employed person or an unemployed person, an unskilled worker or a managing director, and a lorry driver or a teacher, and to register how easy or difficult they found the choice (Charny, Lewis et al. 1989). The results are given in Table 2, and show a preference for the employed over the unemployed, and for the teacher over the lorry driver, and yet for the unskilled worker over the director. This provides ambiguous evidence of social support for indirect benefits, since it is not clear what factors influenced subjects' choices, particularly in relation to the latter two pairs, as occupation may be valued in terms of social contribution or for

Table 3. Studies of Social Preferences Concerning Indirect Costs and Benefits

Study	Country	Number of Subjects	Type of Subjects	Elicitation Method
(Nord, Richardson et al. 1995b)	Australia	551	GenPop[a]	DCM[d]
(Dolan, Cookson et al. 1999)	England	60	Patients	SGD[e]
(Neuberger, Adams et al. 1998)	England	1,300	GenPop/FDs[b]/Gas[c]	DCM
(Charny, Lewis et al. 1989)	Wales	719	GenPop	DCM

a   GenPop = General Population
b   FDs = Family Doctors
c   Gas = Gastroenterologists
d   DCM = Discrete Choice Method
e   SGD = Small Group Discussion

other reasons (Katz 1970, pp. 676-7; Tancredi 1982, p. 98). It is notable that a large number of respondents (50 per cent) made no choice, even though "the interviewers were instructed not to offer the possibility of not making the choice," and to record a median score "if the respondent persisted in not making a choice" (Charny, Lewis et al. 1989, p. 1334). The large "no choice" response raises the suspicion that some subjects may have preferred to give equal priority to each member of the pair if this had been an option.

The importance of equity was confirmed in a study of the effect of discussion and deliberation on the public's views of priority setting undertaken by Dolan, Cookson et al. They asked a random sample of 60 patients in the UK whether some groups of patients should have more or less priority for treatment than others (Dolan, Cookson et al. 1999). Of those surveyed, 97 per cent thought the unemployed should have the same priority for treatment as the employed, and 95 per

cent would give the same priority to those who "contributed a lot" and to those who did not. Discussion and deliberation had no effect upon the first response, and a negligible effect upon the second response.

In a US study, Skitka and Tetlock asked subjects to rate a number of allocation procedures on an "appropriateness scale", ranging from "extremely inappropriate" to "extremely appropriate". Subjects rated need (e.g. "allocating resources to those who are the sickest") as the most appropriate way of setting priorities. The two criteria that rated lowest were merit (i.e. "priority should be based on the contributions people have made to society") followed by market based allocation ("priority should be given to the highest bidder"). These last two were rated as the "most inappropriate ways to allocate resources" (Skitka and Tetlock 1992, p. 509). The low rating given to merit again casts doubt on public support for the inclusion of indirect benefits, at least on the assumptions that social contribution grounds a merit-based claim, and that past contribution is an indicator of future contribution.

PRESERVATION OF HOPE

Some illnesses and injuries are such that the best treatments for them are relatively ineffective. However, studies suggest that people are reluctant to abandon patients with illnesses that have only "cost-ineffective" therapies. There is some evidence, though it is inconclusive, that people are willing to sacrifice aggregate health gains in order to preserve the hope of treatment for everyone.

In an Australian study, Nord, Richardson and colleagues asked 119 interviewees to choose between three different rules for prioritising among high-cost and low-cost patients (Nord, Richardson et al. 1995b). Subjects were made aware of the implications of these rules in terms of the number of people that could be treated, were asked to consider that the rules might affect themselves, and were presented with brief arguments in favour of each rule. Rule A would allocate all of the available money ($1 million) to the treatment of patients with illness X, at a cost of $20,000 per patient, and would allocate no money to the treatment of patients with illness Y, at a cost of $100,000 per patient. This means that 50 people with illness X would be treated and no one with illness Y would be treated. Rule B was "first come, first serve." This means that 10 people with illness X would be treated and 8 people with illness Y would be treated. Participants' choices are summarised in Table 4 under the heading Frame 1. They show that 31 per cent of participants chose rule A and the majority, 69 per cent, chose rule B.

After choosing between A and B, a third "compromise" rule was offered for consideration. This rule stated that priority should be given to patients with illness X, but that some capacity should be allowed for the treatment of patients with illness Y. Subjects were given a brief account of the sort of consideration that might be offered for rule C, which explicitly mentioned hope of treatment: "The advocates of this rule argue that it would be unfair to completely exclude any patient group from the possibility of receiving treatment. They also argue that by assuring everybody some chance of treatment, there would always be hope whatever illness one got and this would be valuable in itself" (Nord, Richardson et al. 1995b, p. 93). The results are given in Table 4 under the heading Frame 2. They show that 54 per cent of the subjects who chose rule A would change to rule C, and 52 per cent of subjects who chose rule B would change to rule C. "Overall, rule C was the preferred choice, being selected by 63 (53%) of the 119 subjects" (Nord, Richardson et al. 1995b, p. 86). Significantly, both rule B and rule C offer hope of treatment, and only 14 per cent of subjects preferred rule A, the most cost-effective option, to both rule B and rule C. Finally, those who preferred rule C were shown five possible ways of dividing the budget between the high-cost and the low-cost patients. The results are given in Table 5. They show,

for example, that of those subjects who preferred rule C, the majority, 48 per cent, chose to treat 30 patients with illness X and 4 patients with illness Y, making a total of 34 patients treated out of a possible 50.

Table 4. Choices Among Three Rules for Resource Allocation

Frame 1			Frame 2					
A vs B	Number	%	A vs C	Number	%	B vs C	Number	%
A	37	(31)	A	17	(46)	B	39	(48)
B	82	(69)	C	20	(54)	C	43	(52)
Total	119	(100)		37	(100)		82	(100)

Source: (Nord, Richardson et al. 1995b)

Table 5. Allocation of $1Million to Two Illnesses

	Frame 3				
	Numbers treated under each option				
Illness	I	II	III	IV	V
X	10	20	30	40	50
Y	8	6	4	2	0
Total	18	26	34	42	50
	Number (%) of subjects selecting each option				
	3 (5)	17 (27)	30 (48)	9 (14)	4 (6)

Source: (Nord, Richardson et al. 1995b)

In another study, Ubel and Loewenstein measured the relative importance people place on prognosis and retransplantation status in distributing scarce transplantable livers (Ubel and Loewenstein 1995). Participants were asked to allocate 100 livers among 200 patients, 100 of whom have a 70 per cent chance of survival and 100 of whom have a 30 per cent chance of survival. Subjects were divided into two groups. Group 1 were told that the different prognoses were based on the results of a blood test. Group 2 were told that the patients with a 70 per cent chance of surviving were first-time transplant recipients, whereas the patients with a 30 per cent

Table 6. Distribution of Transplantable Livers to the Group with 70% Chance of Survival

% of organs distributed to group #1 (with 70% chance of survival)	Blood marker survey respondents (n = 67)	Retransplant survey respondents (n = 71)
< 50	4 (6)	0 (0)
50	25 (37)	19 (27)
51-99	26 (39)	39 (55)
100	12 (18)	13 (18)

Source: (Ubel and Loewenstein 1995)

chance of survival were retransplant patients. The percentage of organs subjects would allocate to each group of patients is shown in Table 6. Subjects asked to allocate on the basis of prior transplant history gave more organs to the better prognostic group than did subjects asked to allocate on the basis of a blood marker. However, the vast majority of subjects in both groups chose to give some organs to the worst prognostic group, with less than 20 per cent choosing to

maximise lives saved. Reflecting on these results, Ubel and Loewenstein speculate that the reluctance of subjects to allocate cost-effectively, "may reflect the difficulty subjects have abandoning any group of candidates…. This reasoning would help explain why some respondents chose to give over 90% of the organs to the better prognostic group, as if saying that although prognosis is important, some amount of organs should be set aside to give hope to the other candidates" (Ubel and Loewenstein 1995, pp. 149-150).

This result was born out by another study undertaken by Ubel and Loewenstein that also focused on the views of the public concerning the allocation of scarce organs (Ubel and Loewenstein 1996a). This time participants were asked to distribute 100 livers between 200 children waiting for a transplant. The participants were told that the children were divided into two groups of 100 on the basis of a blood test, each having a different prognosis. One group of subjects was asked

Table 7. Allocation Decisions: Percent of Organs Allocated to Better Prognostic Group

Percent of organs given to better prognostic group	Number (%) of subjects making choice in each survey					
	80/70 ($n = 32$)	80/50 ($n = 33$)	80/20 ($n = 34$)	40/25 ($n = 35$)	40/10 ($n = 35$)	Total ($n = 169$)
< 50	1 (3)	0 (0)	0 (0)	3 (9)	1 (3)	5 (3)
50	17 (53)	11 (33)	9 (26)	14 (40)	5 (14)	56 (33)
51-75	7 (22)	9 (27)	7 (21)	5 (14)	10 (29)	38 (22)
76-99	3 (9)	2 (6)	10 (29)	4 (11)	13 (37)	32 (19)
100	4 (13)	11 (33)	8 (24)	9 (26)	6 (17)	38 (22)

Source: (Ubel and Loewenstein 1996a)

In all cases, the group 1 patients were those with the better prognoses

to distribute the livers between one group of children with an 80 per cent chance of survival and another with a 70 per cent chance. The results are given in Table 7, along with four other pair-wise comparisons (80/50, 80/20, 40/25, 40/10). Of those who participated in the study, 78 per cent chose not to distribute the organs in the most cost-effective manner, choosing instead to allocate some organs to the children in the cost-ineffective categories. Significantly, the most

Table 8. Subjects' Reasons for Making Allocation Decisions: Distribution of Responses by Allocation Choice

Category of response*	Allocation choice			
	≤ 50% of organs to the better prognostic group	51-99% of organs to the better prognostic group	100% of organs to the better prognostic group	Total
Increase survival	2	58	36	96
Deserve a chance	44	37	0	81
Prognosis unpredictable	16	8	0	24
Good prognosis	8	2	0	10
Other	7	6	1	14

Source: (Ubel and Loewenstein 1996a)

* Data reflect both responders with multiple answers and nonresponders

popular strategy - chosen by 33 per cent - was to distribute the organs equally between the two diagnostic groups. Ubel and Loewenstein also asked participants to explain their allocation decisions. The most frequently cited reason was "improved survival". The responses of 96 subjects fell into this category, and show that allocative efficiency was an important consideration. However, 81 participants also explained their decision with comments such as "everyone deserves a chance," "everyone deserves an equal chance," and "needy people deserve transplants, whatever their chance of survival." This was the second most numerous category of response (see Table 8), and indicates that "[m]any subjects felt that everyone with some chance of benefiting from transplant deserves some chance at receiving available organs … even if this means poorer outcomes" (Ubel and Loewenstein 1996a, p. 1052).

Table 9. Policy Recommendations Made by the Survey Participants

	Number of Respondents (%)		
Recommendation	Prospective Jurors	Medical Ethicists	Decision-Making Experts
Test 1 (saves 1000 lives)	319 (56)	39 (53)	30 (41)
Test 2 (saves 1100 lives)	240 (42)	32 (43)	41 (56)
Refusal to make a recommendation*	9 (2)	3 (4)	2 (3)

Source: (Ubel, DeKay et al. 1996b)

* These participants provided written explanations for their refusal to make a policy recommendation

The above studies provide some evidence that people want to preserve the hope of treatment for patients who fall into "cost-ineffective" treatment categories, even if this means accepting a lower level of health production overall. In another study Ubel, DeKay et al. found that people are also willing to accept a lower level of health production in order to ensure that everyone within a treatment category receives treatment (Ubel, DeKay et al. 1996b). In this study, 568 prospective jurors, 74 members of the American Association of Bioethics, and 73 members of the Society for Medical Decision Making were asked to choose between two different screening tests for colon cancer. Test 1 could be offered to all people at risk of colon cancer, and would prevent 1000 deaths. Test 2 could be offered to half of those at risk, because it is more expensive, but would prevent 1100 deaths, because it is more effective. Table 9 gives respondents' choices. Fifty-six per cent of jurors and 53 per cent of medical ethicists chose test 1, ensuring that all of those in the population at risk would receive the test, even though this would result in the avoidable loss of 100 lives. Even 41 per cent of decision-making experts chose test 2. The reasons

Table 10. Survey Participants' Explanations for their Policy Recommendations

Explanation*	Those Who Recommended Test 1 (N = 388)	Those Who Recommended Test 2 (N = 313)	Total (N = 701)
Fairness	256	49	305
Improved survival	13	229	242
Political appearance	18	0	18
Small difference in survival	12	0	12
Highlighting need for funding	0	5	5
Other	64	48	112

Source: (Ubel, DeKay et al. 1996b)

* Some participants provided more than one explanation for their policy recommendations

participants gave for their decisions are summarised in Table 10. The majority of those who favoured test 2 cited "improved survival" in support of their choice. The majority of those who favoured test 1 cited "fairness". The sort of response that Ubel, DeKay et al. placed under the heading of fairness included: "It would be unfair to offer the test only to half the people," "Equity is more important than efficiency," and "It is not fair to randomly distribute health care." The authors suggest that participants rejected CEA because it pays insufficient attention to equity: "a large number of respondents rejected the more effective test because they thought it would be inequitable to offer it to half the people when a less effective test could be offered to everyone" (Ubel, DeKay et al. 1996b, p. 1176).

In a British study, Ratcliffe used "social" conjoint analysis (CA) to test public preferences for the allocation of donor liver grafts for transplantation (Ratcliffe 2000). In the first section of the questionnaire subjects were asked to rank the following five criteria in order of importance, in the context of scarce organ allocation: expected length of survival, whether the patient's liver disease was naturally occurring or alcohol induced, the time spent on the waiting list for a transplant, the age of the patient, and whether the patient was a primary or re-transplant candidate. "The results from this study indicate that the majority of the members of the general public surveyed agree

Table 11. Studies of Social Preferences for the Preservation of Hope

Study	Country	Number of Subjects	Type of Subjects	Elicitation Method
(Nord, Richardson et al. 1995b)	Australia	551	GenPop[a]	DCM[b]/SWTP[c]
(Ubel and Loewenstein 1995)	USA	138	GenPop	OA[d]
(Ubel and Loewenstein 1996a)	USA	169	Prospective Jurors	OA
(Ubel, DeKay et al. 1996b)	USA	715	PJ[e]/AAB[f]/SMDM[g]	DCM
(Ratcliffe 2000)	England	303	University Employees	OA/SCA[h]

a   GenPop = General Population
b   DCM = Discrete Choice Method
c   SWTP = Social Willingness to Pay
d   OA = Organ Allocation
e   PJ = Prospective Jurors
f   AAB = Members of the American Association of Bioethics
g   SMDM = Members of the Society for Medical Decision Making
h   SCA = Social Conjoint Analysis

that the capacity to survive and benefit should be the most important criterion in the selection of liver transplant recipients" (Ratcliffe 2000, p. 145). However, in the second section of the questionnaire, subjects were confronted with the opportunity cost of adhering strictly to health maximisation as an allocation strategy. In particular, they were asked to allocate100 donor livers between two groups of 100 patients awaiting life-saving treatment. In completing this task the majority of respondents were prepared to allocate some organs to the group with the worst prognosis, thereby trading-off some gain in the efficiency of the transplantation programme for a more equitable allocation of organs. "It would appear therefore, that within the context of a scarcity of donor organs, respondents felt that a proportion of individuals in both groups should be given some chance or hope of receiving a transplant, regardless of their situation" (Ratcliffe 2000, p. 145).

THE RULE OF RESCUE

Jonsen coined the term "Rule of Rescue" (RR) to describe the imperative people feel to rescue identifiable individuals facing avoidable death without giving too much thought to the opportunity cost of doing so (Jonsen 1986). It has been described as "a perceived duty to save endangered life where possible" (Bochner, Martin et al. 1994, p. 901), as "the sense of immediate duty that people feel towards those who present themselves to a health service with a serious condition" (Nord, Richardson et al. 1995b, p. 90), as "an ethical imperative to save individual lives even when money might be more efficiently spent to prevent deaths in the larger population" (Dougherty 1993, p. 1359), as "the powerful human proclivity to rescue a single identified endangered life, regardless of cost, at the expense of many nameless faces who will therefore be denied health care" (Osborne and Evans 1994, p. 779).

According to Hadorn, the RR played an important role in the Oregon priority-setting exercise for allocating resources in the state's Medicaid programme (Hadorn 1991; Hadorn 1996). In 1990 the Oregon Health Services Commission produced a priority list of health services. It ranked some 1,600 pairs of treatments and conditions, for example, "medical therapy for hypoglycemic coma," "septoplasty/repair/control of hemorrhage for life-threatening epistaxis," "stabilization for open fracture of the ribs and sternum". Rankings were based on the expected outcomes with and without treatment, the duration of the treatment effect, the expected quality of life of patients assessed on a scale calibrated by Oregon residents, and the cost of treatment. The initial list was never forwarded to the legislature because of the counterintuitive ordering that resulted, especially concerning life saving treatments. For example, dental caps for pulp or near pulp exposure were assigned a higher priority than surgical treatment for ectopic pregnancy (salpingectomy/salpingoophorectomy), and splints for temporomandibular joint disorder were ranked higher than appendectomies for appendicitis (Dixon and Welch 1991; Hadorn 1991). A revised list was produced a year later that saw all treatment of life-threatening conditions placed in a separate high-priority category. Hadorn argued that this occurred because, "any plan to distribute health care services must take human nature into account if the plan is to be acceptable to society. In this regard there is a fact about the human psyche that will inevitably trump the utilitarian rationality that is implicit in cost-effectiveness analysis: people cannot stand idly by when an identified person's life is visibly threatened if rescue measures are available" (Hadorn 1991, p. 2219).

A new form of the RR was articulated by Ubel, Arnold and colleagues in their analysis of organ transplantation policy in the US (Ubel, Arnold et al. 1993). The authors noted that between 10 per cent and 20 per cent of available hearts and livers in the US were allocated to re-transplant patients, despite the fact that first-time recipients have a higher one-year survival rate. Reflecting on this, they concluded that the system as it operated at the time was ethically indefensible: "Our moral duty to direct scarce, lifesaving resources to those likely to benefit from them, suggests that, all other things equal, primary transplant candidates should receive priority because their mortality after transplantation is lower" (Ubel, Arnold et al. 1993, p. 2469). The authors argued that the duty transplant teams feel not to abandon their patients partially explains the failure to include re-transplantation status among the eligibility criteria for a heart or liver transplant. "Surgeons feel an even stronger duty to help patients on whom they have operated. This is likely to affect how transplant teams feel about transplant candidates on whom they have previously performed a transplant" (Ubel, Arnold et al. 1993, p. 2471). In brief, health-care professionals feel a duty to rescue identifiable patients - patients on whom they have previously operated - especially when they face avoidable death, and rescue measures are available.

Arguably, the RR is an instance of the more general tendency to extend special consideration to those facing death, whether or not death can be averted. Even when they are equally effective in

purely medical terms, for example, palliative measures for patients with terminal conditions - patients at the end of life - have a value not possessed by palliative measures provided to other patients. Palliative care for patients with terminal conditions receives extra weight because it is offered in the face of death, not because it will avert death (Menzel, Gold et al. 1999, p. 10). Consistent with this, in a priority-ranking exercise in Britain, the general public gave the second highest ranking out of 16 health services to, "special care and pain relief for people who are dying," the first ranking being given to "treatments for children with life threatening illness" (Bowling, Jacobson et al. 1993). This result was confirmed in a subsequent study (Bowling 1996, p. 670). Similarly, Hadorn noted that when the Oregon Health Services Commission was developing its final priority list of health services, palliative care for terminally ill patients, including hospice programmes and pain medication, was ranked relatively high (Hadorn, 1991b, p. 12). Conventional CEA does not distinguish between interventions offered in the face of death and other interventions, unless the QALY gains themselves are expected to be different.

A conspicuous feature of the RR is the special consideration given to identifiable individuals. Jenni and Loewenstein explain the "identifiable victim effect" in terms of the public preference for - or greater toleration of - wide rather than narrow distributions of risk (Jenni and Loewenstein 1997). For example, people are more concerned about the risks of a vaccination programme if only 10 per cent of the population are susceptible to adverse side effects than if the whole population is susceptible, even if the number of people who will die is, say, 1000 in either case (Ritov and Baron 1990). Jenni and Loewenstein speculate that the "identifiable victim effect" may largely be explained by this antagonism towards concentrated rather than shared distributions of risk: "In effect, identifiable victims become their own reference group, creating a situation where n out of n people will die if action is not taken" (Jenni and Loewenstein 1997, p. 238).

In support of this, Jenni and Loewenstein tested four possible explanations for the "identifiable victim effect". For example, they asked subjects to rate on a scale of one to five the importance of eliminating risk in a pair of scenarios that differed in the amount of detail they contained about a traffic accident victim. They found that *vividness* does not significantly increase the importance of undertaking a rescue attempt. This was confirmed when they asked another group of subjects to choose, without rating, the scenario in which it is more important to eliminate risk (see Table 12). Another pair of scenarios tested the effect of *certainty*. One of these stated that 10 deaths would result from the sale of a contaminated food source. The other stated that "the best estimate is that 10 people will die, but more or fewer may die depending on the prevalence of the allergy" (Jenni and Loewenstein 1997, p. 244). Subjects undertaking the rating task - subjects asked to rate on a scale of one to five the importance of eliminating risk in the scenarios - were more concerned to prevent certain deaths than probabilistic deaths, but the subjects undertaking the direct comparison task - subjects asked to choose, without rating, the scenario in which it is more important to eliminate risk - did not support this (Table 12). A third pair of scenarios tested the significance of *timing*. In one case an individual had been exposed to a toxic pesticide and had to be located. In the other, the individual was about to be exposed unless she could be located first. Jenni and Loewenstein found no evidence that *ex post* (remedial) actions are more important than *ex ante* (preventative) ones. (In fact, subjects asked to undertake the rating task indicated support in the opposite direction.) The final pair of scenarios tested whether the *proportion* of the risk group that can be saved is important. One scenario stated that, of the 50,000 people at risk from traffic accidents, 25 could be saved by a new safety programme. The other stated that, of the 25 people at risk on a specific highway interchange, all of them could be saved by a new safety programme. In both the rating task and the comparison task, there was significantly more support for rescues that save a large portion of the reference group.

If Jenni and Loewenstein are correct, people acting on the RR see the identifiable individual as the relevant reference group. Of course, this ignores, or underestimates, the claims of those anonymous individuals who could (individually and collectively) benefit, perhaps even more, from the expenditure of the same resources. As Jenni and Loewenstein conclude: "Given that reference group size is often a matter of framing – a reference group of arbitrary size can be specified for virtually any hazard – a blanket endorsement of a policy that treats fatalities differently based on what proportion of the reference group they compose is normatively dubious" (Jenni and Loewenstein 1997, p. 240). On the other hand, people obtain benefit from the belief that they live in a caring and humane society, and the observation of attempts to save life, whether heroic or more mundane, reinforces this (MacLean 1986, p. 87; Eddy 1994, p. 1795). As Mooney observes: "even the detached bureaucratic utilitarian can plausibly calculate that encouraging sympathy among members of a community and between conflicting communities will make the world a better place" (Mooney 1992, p. 1223).

Table 12. Number of subjects Rating Each Scenario as More Important

Vividness	Vivid	Anonymous	Equally important	Significance
Ratings	8 (.06)[a]	13 (.15)	64 (.79)	NS
Direct Comparison	4 (.10)	1 (.03)	35 (.88)	NS
Certainty and uncertainty	Certain	Uncertain	Equally important	Significance
Ratings	26 (.30)	6 (.07)	54 (.63)	<0.005
Direct Comparison	11 (.29)	8 (.21)	19 (.50)	NS
Proportion of the reference group	Smaller reference group	Larger reference group	Equally important	Significance
Ratings	44 (.51)	13 (.15)	29 (.34)	<0.001
Direct Comparison	21 (.51)	3 (.07)	17 (.41)	<0.001
Ex post/Ex ante	Ex post	Ex ante	Equally important	Significance
Ratings	12 (.14)	24 (.28)	50 (.58)	(b)
Direct Comparison	7 (.17)	9 (.22)	25 (.61)	NS

Source: (Jenni and Loewenstein 1997)

a   Numbers in parentheses show the fraction of respondents answering in each order

b $p < 0.05$, significant in opposite direction from prediction

While the RR implicitly attaches special value to interventions offered in the face of death, and especially to interventions that will avert death, it can also be a factor when life is not endangered (Hadorn 1991, p. 2219). For example, children with physical deformities or disfigurements are sometimes flown from poor countries to wealthier countries for treatment. Their plight evokes the same "shock-horror" reaction as someone whose life is in immediate danger, and the same tendency to disregard, or underestimate, the value sacrificed by not putting resources to the best alternative use.

ADAPTATION TO ILLNESS AND DISABILITY

Permanently disabled and chronically ill patients often rate their own quality of life higher than do healthy people imagining themselves in these states. For example: Churchill, Torrance and colleagues found that dialysis and transplant patients rated their current health state higher than nephrologists and nurses (Churchill, Torrance et al. 1987); Boyd, Sutherland and colleagues found that colostomy patients rated hypothetical health states related to their own higher than

physicians or healthy volunteers (Boyd, Sutherland et al. 1990); Hall, Gerard et al. found that women with breast cancer rated cancer scenarios higher than women without breast cancer (Hall, Gerard et al. 1992); Hurst, Jobanputra et al. found that rheumatoid arthritis patients rated their health status higher than the general public (Hurst, Jobanputra et al. 1994); Samsa, Matchar et al. found that patients with stroke rated a hypothetical stroke scenario higher than patients with TIA (transient ischemic attack) or asymptomatic patients at risk for stroke (Samsa, Matchar et al. 1998).

Others studies have shown that patients sometimes assign lower values to their health state in comparison with other groups (Rosser and Kind 1978; Badia, Diaz-Prieto et al. 1996), and some studies have detected roughly equivalent ratings (Wolfson, Sinclair et al. 1982; Balaban, Sagi et al. 1986; Llewellyn-Thomas, Sutherland et al. 1991; Tyc 1992; Badia, Fernandez et al. 1995; Hadorn and Uebersax 1995; Badia, Diaz-Prieto et al. 1996; Revicki, Shakespeare et al. 1996; Dorman, Waddell et al. 1997; Jenkinson, Gray et al. 1997). However, in their review of 38 studies in this area, De Wit, Busschbach et al. (2000) note that of the 27 studies that uncovered differences between patients and other groups, 22 reported higher patient values, and only 2 showed lower patient values. From this they conclude: "current evidence would be most supportive of the conclusion that patients' values are higher than values of other rater groups" (De Wit, Busschbach et al. 2000, p. 110). Indeed, not only do patients tend to assign higher values to their health state in comparison with other groups, "in some cases they rank these states in an order different from that of the general population" (Sackett and Torrance 1978, p. 703).

One reason why patients assign higher values to their health state in comparison with other groups, is because patients adapt to their condition. As Antonak and Liveh observe, several reaction phases are likely after a traumatic event or the diagnosis of a chronic and disabling illness: shock, anxiety, denial, depression, internalised anger, and externalised hostility. In most cases, however, these are followed by acknowledgement ("the cognitive recognition (i.e. intellectual acceptance) of the functional implications stemming from the impairment and the gradual integration of the functional limitations associated with one's condition into one's self-concept") and adjustment ("an affective internalization (i.e. emotional acceptance) of the functional implications of an impairment into one's self-concept coupled with behavioral adaptation and social reintegration into the newly perceived life situation" (Antonak and Liveh 1995, p. 1100)). This raises the question of whose preferences should be used in determining the (dis)utility of health states for the purposes of programme evaluation, and whether adapted or non-adapted preferences should be used. If the non-adapted preferences of the general public are used in economic evaluations, the gains from a health programme or service, measured for example in QALYs, may appear greater than if the adapted preferences of patients are used. In some cases the difference may be significant - for example, 0.44 QALYs gained per dialysis patient using adapted preferences compared with 0.61 QALYs using non-adapted preferences (Sackett and Torrance 1978) - so resolving the issue is of considerable policy relevance.

There are a number of arguments in favour of using the adapted values of actual patients. Primarily, those who have had first-hand experience of a health state are better placed to judge how distressing or disabling it is. As Menzel, Dolan et al observe: "Patients certainly have a better understanding of what life is like in states of impaired health, and it is their preferences, whether significantly influenced by adaptation or not, that represent what is actually experienced in the conditions that health services aim to remedy or prevent" (Menzel, Dolan et al. 2002, p. 2150). On the other hand, since it is the resources of society that are being used to fund public health programmes and services, the construction of health-state measures should arguably reflect the preferences of the general public, even if those preferences are imperfectly formed.

There are also arguments in favour of using community preferences that are based more closely on the process of adaptation itself. For example, adapted patients may be in denial about the full extent of their disability, or may have forgotten what full health would allow them to achieve (Menzel, Dolan et al. 2002). On the other hand, as a result of adapting to their illness or disability patients may have learned new skills to achieve their goals, or may have substantially altered their goals to reflect their changed circumstances more realistically (Calman 1884; Knussen and Cunningham 1988; Allison, Locker et al. 1997; Menzel, Dolan et al. 2002). Partly reflecting these possibilities, Warr, Jackson et al. distinguish between *resigned* adaptation, which involves passive acceptance of one's condition, or reducing one's aspirations, and *constructive* adaptation, which involves active attempts to mitigate the effects of illness or disability by the adoption of new but no less challenging goals (Warr, Jackson et al. 1988).

Controversially, the World Health Organization burden of disease study used non-adapted values (Murray and Lopez 1996). Similarly, the US Public Health Service Panel on Cost-Effectiveness in Medicine (Gold, Siegal et al. 1996) advocated using the non-adapted values of the general public. By contrast, Menzel, Gold et al. (1999), Nord (1999, pp. 82-90), and Nord, Pinto et al. (1999) favour the use of adapted preferences. It is surprising, given the emphasis increasingly placed on public participation in health-care decision making (Lenaghan 1999; Mossialos and King 1999; Roberts, Bryan et al. 1999), that no studies have been undertaken that ask the public whether adapted or non-adaptive values should inform health care decision-making,

The ethical problems surrounding the issue of adaptation become evident when the more extreme forms of adaptation are contemplated. For example, in a recent issue of the *British Medical Journal* Savulescu argues that deaf couples undergoing IVF have a right to use pre-implantation genetic diagnosis to select a deaf embryo (Savulescu 2002). Many deaf people, having adapted "perfectly" to their condition, reject the "pathological" view of deafness, and see themselves as a group sharing a common language (for example, American Sign Language) and a common culture – "deaf culture", which is different from but not inferior to "hearing culture". From this point of view it is wrong to use the non-adapted values of the general community when assessing the benefits of programmes aimed at preventing or curing deafness (or Down's syndrome or dwarfism). However, at least one input into this debate should be the general public, and to date this has not happened.

THE *EX ANTE/EX POST* DISTINCTION

Health states resulting from an intervention may be judged *ex ante* or *ex post* – before the outcome is experienced or after the health state has been experienced. If it is thought that economic evaluations should be based on data from health states that have actually occurred, then *ex post* judgements should be used. On the other hand, *ex ante* judgements are able to capture pre-outcome sources of utility, such as reassurance and the avoidance of regret and uncertainty. As argued by Pope (2004), these pre-outcome emotions are potentially very important to health state evaluation, and drive a wedge between the utility of outcomes and expected utility as perceived from the *ex ante* perspective. Little attention has been paid to the *ex ante/ex post* distinction in the literature and what attention it has received has been theoretical. As a result, it is unclear whether members of the public in Australia, or other countries, want their national health schemes to pay for pre-outcome sources of utility.

Special difficulties surround *ex ante* measurement, which in large part explain the divergence between "decision utility" (the utility expected at the time of decision) and "experience utility" (the utility actually experienced as a result of a decision) (Sunstein 1997, p. 1184). For example,

people may find it hard to imagine what a health state will be like *ex ante*. They may have to rely on health state descriptions that are incomplete or too hard to visualise (Ubel, Loewenstein et al. 2003). Also, they may have alternative sources of information about the health state (health professionals, the media, friends and family), not all of which are accurate, and which colour the evaluation of the health state from the *ex ante* perspective. Finally, even if the information is accurate, from the *ex ante* perspective people may focus excessively on one aspect of a health state at the expense of a more balanced view, and this may differ from individual to individual. That is, judgements made from the *ex ante* perspective may be subject to a "focusing illusion" (Eisenhardt 1989; Nutt 1998; Ubel, Loewenstein et al. 2001). Rightly, measurement problems of this sort are generally not accepted as being decisive in the choice of measurement strategy. Unless the problems are extreme, there is widespread support for the dictum that it is preferable to carry out imperfect measurement of the right concept than better measurement of the wrong concept. However, this leaves the question of which is the right concept unanswered – that is, whether *ex ante* or *ex post* measurement should be used in economic evaluations.

Resolving this issue has potentially significant implications for the choice of subject for the purposes of measuring health-related quality of life. If the *ex ante* perspective is considered appropriate, a cross-section of the general population is the obvious source of utility scores in economic evaluations, since the pre-outcome emotions of the general public (fear, anticipated regret, anxiety, and so on) have not been transformed by the process of adaptation to the health state (Menzel, Dolan et al. 2002; Sharma, Stano et al. 2004). By contrast, gold standard *ex post* evaluation of health states is clearly achieved when patients themselves are consulted, since only patients have experienced the health state in question. This distinction is not clearly reflected in the practice of measurement. For pragmatic reasons a cross-section of the public, implying the *ex ante* perspective, is usually questioned about health states envisaged in real time, with no pre-outcome feelings – a perspective more suited to *ex post* measurement. Resolving the *ex ante/ex post* issue may therefore provide enlightenment on the choice of subject for health state measurement.

The potential importance of reassurance, as a source of *ex ante* utility, is illustrated in a study by Bytzer, Hansen et al. Two approaches may be adopted when dyspepsia is initially diagnosed (which is often functional): investigation to try and discover the cause (e.g. endoscopy), or treatment (e.g. with H_2 blockade). The study by Bytzer, Hansen et al. failed to detect any significant differences, in terms of symptom relief or health-related quality of life after one year, between groups receiving an endoscopy and those receiving treatment (Bytzer, Hansen et al. 1994; Thompson 1995). Despite this, the study also found greater *patient satisfaction* among patients managed by prompt investigation. Tebaldi and Heading explain this in terms of the *reassurance* that investigation brings (Tebaldi and Heading 1998). Patients often seek medical attention out of fear their symptoms might indicate the presence of some serious underlying cause, with symptom relief being a secondary consideration. In the case of dyspepsia, in particular, the authors argue that reassurance should be a part of the clinical management of the condition, and should also be included in economic evaluations of treatments of the condition: "for many patients with dyspepsia it is not symptom resolution but knowledge that the symptoms are not 'serious' that is their main concern. If this is important for the patients it must somehow be assessed and costed in economic appraisals of dyspepsia management" (Tebaldi and Heading 1998, p. 17).

Studies of patients' attitudes towards screening programs provide further evidence of the potential importance of reassurance. For example, Santalahti, Aro and colleagues investigated women's reasons for participating in two prenatal screening tests: serum screening and mid-trimester ultrasound screening. "When women's personal reasons for participation were asked

about, reassurance was the single most often-mentioned item in both the serum screening and the ultrasound groups" (Santalahti, Aro et al. 1998, p. 156). Of participants, 41 per cent cited reassurance about the health of the fetus among their reasons for participating in the serum screening test, and 65 per cent cited this reason for undergoing ultrasound screening, in an open question format. In a separate study, Kornman, Wortelboer, et al. asked women undergoing second-trimester screening for fetal Down's syndrome whether they would have preferred the test earlier if it was available. "Seventy-six per cent of those who participated in the second-trimester screening programme would have preferred the test to have been in the first trimester, mainly because of the easier termination of pregnancy and/or the earlier reassurance provided" (Kornman, Wortelboer et al. 1997, p. 1011). This was confirmed in a study by de Graff, Tijmstra, and colleagues, who examined the preferences of two groups of women: those at high risk of a fetal abnormality (Down's syndrome) and those at low risk. Of those in the first group, 95 per cent stated a preference for first-trimester serum testing, and of those in the second group, 86 per cent preferred an earlier test. "The main advantages for earlier screening were given as earlier reassurance and 'easier' termination in the case of an affected fetus" (de Graff, Tijmstra et al. 2002, p. 627). Reassurance has also been revealed as a significant motivation for women undergoing breast cancer screening (Brain, Gray et al. 2000; Farmer 2000; Holloway, Porteous et al. 2004).

In many of these cases seeking reassurance is sensible and cannot be separated from the desire to prevent an adverse outcome or serious illness. However, it raises the possibility that reassurance *per se* might be of value to patients independently of any health effects that might accompany it. If so, it is important to find out whether the general public believes that reassurance should be taken into account in economic evaluations of health programmes and services.

Expected utility theory, as axiomatised by von Neumann and Morgenstern (1947), is a powerful model of choice under uncertainty. However, an impressive body of experimental findings provides evidence that people systematically violate the axioms of EUT (Kahneman, Slovic et al. 1982; Schoemaker 1982; Loomes and Sugden 1987; Kagel and Roth 1995; Kahneman and Tversky 2000; Luce 2000). Its theoretical validity as a positive or normative decision rule is also contestable, inter alia, because of its exclusion of pre-outcome emotions. In response to this, alternative models of choice under uncertainty have been developed, such as "regret theory" (Bell 1982; Loomes and Sugden 1982; Anand 1985; Bell 1985; Loomes and Sugden 1987; Loomes 1988). Regret theory is based on the premise that individuals are concerned not only with the outcomes of their decisions, but with minimising the chance that they will feel regret at having made a wrong decision. Similarly, disappointment theory is based on the premise that individuals are concerned with avoiding disappointment when a decision turns out worse than expected. Salkeld, Ryan et al. define regret as "a psychological reaction to making a wrong decision" and disappointment as "the psychological reaction to the outcome of an event not living up to its expectations" (Salkeld, Ryan et al. 2000, p. 269). Note that regret violates the independence axiom of EUT. The value of an alternative depends on the other alternatives available when the choice is made: the better (worse) the outcomes associated with these other alternatives, the greater is the potential for regret (rejoicing) (Stewart, Chater et al. 2003).

Smith, Hall et al. found that patients with colon cancer would choose adjunct chemotherapy to accompany surgery, rather than surgery alone, even though the adverse quality-of-life effects of chemotherapy, as assessed by the patients themselves, more than offset the value of the additional years of life (Smith, Hall et al. 1993). Smith postulated that this apparently irrational behaviour occurred because patients wanted to avoid anticipated regret (Smith 1996). The subjects in this study, adopting an *ex ante* perspective, anticipated regretting their failure to

undergo chemotherapy if cancer recurred, and to avoid this were prepared to endure the additional "disutility" of chemotherapy. In fact, the fear of regret was so acute that "patients all felt they had no alternative but to go with the option that offered them the best chance of survival, no matter how small that additional chance, nor how bad the treatment" (Smith 1996, p. 113).

In a UK study, Ryan used (personal) WTP to test whether women (and their partners) who had been through IVF (In Vitro Fertilization) treatment were motivated to undergo that treatment by psychological feelings of regret and disappointment (Ryan 1998). Among other things, respondents were asked how much they would be willing to pay for an IVF attempt. Of these, 229 provided an *ex ante* WTP valuation (either they were currently undergoing IVF but did not know the outcome, or were not currently undergoing IVF but had done so and were prepared to try again) and 78 provided an *ex post* WTP valuation (expressing their WTP for their most recent attempt). Agreement with the statement, "One of the reasons we are trying (or tried) IVF is that in later life I will know we have tried everything possible," was a statistically significant predictor of WTP in the *ex ante* group. (See Table 13.) Ryan comments: "attempting to prevent regret may be an important motivational factor in the decision to go through ARTs [Assisted Reproductive Techniques]" (Ryan 1998, p. 199). Moreover, the more individuals agreed with the statement, "When our first attempt at IVF failed I was surprised," the less they valued assisted reproductive techniques. "This suggests that the psychological feeling of disappointment may be an important factor when looking at total utility from undertaking IVF" (Ryan 1998, p. 199). The significance of regret and disappointment was supported by the responses of the *ex post* group. Although WTP was substantially higher for the *ex ante* group, the *ex post* group also gave a positive valuation to "trying everything possible to have a child." Of the 78 individuals in the *ex post* group, 65 had left the programme without a child. Even so, "the childless still provided a positive valuation for the service" (Ryan 1998, p. 199). The author sums up the study in this way: "The results indicate that the psychological feelings of 'regret' and 'disappointment' may be major motivators for individuals seeking ARTs" (Ryan 1998, p. 198).

Table 13. Response to Attitude Statements

Statement	Disagree (%)[a]	Neutral (%)[b]	Agree (%)[c]	Number of responses
1. One of the reasons we are trying (or tried) IVF is so that in later life I will know that we have tried everything possible to have a child.	6	5	89	458
2. Even if we leave (or left) the IVF programme childless, I believe I will be (am) glad we tried it.	3	3	93	457
3. When we started the IVF programme I was very sure that we would leave it with a child.	40	22	38	456
4. When our first attempt at IVF failed I was surprised.	52	14	34	343

Source: (Ryan 1998)

a   Responded with 1, 2 or 3 on the sevenpoint scale.
b   Responded with 4 on the seven point scale.
c   Responded with 5, 6 or 7 on the seven point scale.

Elstein, Holzman et al. speculate that avoiding anticipated regret explains an anomaly in the prescribing pattern of physicians (Elstein, Holzman et al. 1986). The researchers asked a group of physicians whether or not they would prescribe estrogen for a group of menopausal women.

Twelve written case histories were presented to the physicians that differed along three dimensions: cancer risk, severity of vasomotor symptoms, and osteoporosis risk. In the first part of the study the optimal treatment was calculated based on the physicians' own subjective probabilities and utilities. This suggested that the physicians ought to recommend estrogen treatment, or be indifferent between estrogen and no estrogen. On the contrary, the majority of physicians recommended against estrogen treatment. One possible explanation is that, although estrogen offered the highest expected value based on the physicians' own probabilities and utilities, it also carried a low but increased risk of death. The authors speculate that the physicians' choices were influenced by an attempt to avoid regret (on the part of their patients and possibly themselves), which would be considerable if cancer developed after treatment. "It may well be argued … that human judgement is influenced by aspects of the task that are excluded by the expected utility model but ought to be included: for example, the attribution of responsibility and anticipation of regret" (Elstein, Holzman et al. 1986, p. 255). Commenting on this study, Landman reaches the same conclusion: "a decision that appears incoherent within orthodox decision theory is seen as coherent within a theory that takes regret into account" (Landman 1993, p. 146).

It is uncertain whether members of the Australian public, adopting a social perspective, would be willing to pay, or would be prepared to accept less spending on other health services, to avoid the possibility of regret. As with reassurance, there is virtually no empirical data on social attitudes towards the avoidance of regret per se.

Risk refers to situations where the probabilities associated with the possible outcomes of a decision are known. *Uncertainty* refers to situations where the probabilities are unknown - where the information available to the decision-maker is too imprecise to provide a useful measure of probability. Uncertainty about the future can give rise to intense feelings of apprehension (Caplin and Leahy 2001). For example, with probabilities that are not easily calculated, a treatment may return a patient to full health, may have no effect at all, may kill the patient, or may be of only partial benefit. The uncertainty (or "vagueness" or "ambiguity") that accompanies this situation induces an aversive reaction, the strength of which increases with the degree of uncertainty, the consequences involved, and the period of delay until the uncertainty is resolved (Caplin and Leahy 2001). In apparent support of this, several studies have reported that some subjects, when given the choice, prefer a large electric shock now to a smaller shock in the future. (The "future" may be seconds away or days.) Presumably, this is done to avoid the period of anticipatory anxiety associated with the delayed shock (Cook and Barnes 1964; Loewenstein 1987). "Many subjects choose the larger shock rather than waiting anxiously for the smaller shock" (Caplin and Leahy 2001, p. 59).

Uncertainty aversion has been subject to a good deal of theoretical discussion in the context of EUT, its variants, and rivals (Camerer and Weber 1992; Fox and Tversky 1995; Montesano and Giovannoni 1996; Epstein 1999; Ma 2000; Klibanoff 2001; Di Mauro and Maffioletti 2004), and has received increasing attention in the health context (Camerer and Weber 1992; Andersson and Lyttkens 1999; Andersson and Lyttkens 2000; Oliver 2000; Wakker 2000). The dislike of uncertainty can be seen in the Ellsberg paradox. Here, subjects are asked to choose a preferred lottery from each of two pairs, A and B, and C and D. In Ellsberg's original formulation this involved drawing balls from an urn. The payoffs and probabilities of choosing either a red, black or yellow ball are given in Table 14. Although the urn contains 60 black or yellow balls, the exact percentage of each colour is uncertain. Ellsberg found that large numbers of people preferred A to B and D to C, in contradiction of standard EUT (Ellsberg 1961). This suggests that decision makers give events with unknown probabilities a lower weight in their outcome evaluation. This is different from risk aversion: subjects are not preferring a sure option to a risky one with an equal

or greater expected value. Rather, the subjective probabilities are identical, and choices seem to be shaped by "a third dimension of the problem of choice: the nature of one's information concerning the relative likelihood of events" (Ellsberg 1961, p. 657) – that is, uncertainty per se.

Table 14. Choices in the Ellsberg Paradox

	Red	**Black**	**Yellow**
	30	60	
Lottery **A**	$100	$0	$0
Lottery **B**	$0	$100	$0
Lottery **C**	$100	$0	$100
Lottery **D**	$0	$100	$100

The Ellsberg paradox deals with uncertain *outcomes*. Another possible source of (dis)utility connected with uncertainty concerns *the timing of its resolution* (Mossin 1969; Dréze and Modigliani 1972; Spence and Zeckhauser 1972; Kreps and Porteus 1978; Wu 1999).) Pope refers to the period of time after a choice is made, but before its consequences are known, the "pre-outcome period" (Pope 2004, p. 706). Uncertainty during this period may give rise to disagreeable feelings such as fear and apprehension, or agreeable feelings, such as hope and excitement. Wu notes two general reasons why a person may prefer to have uncertainty resolved immediately. First, it may facilitate *physical preparedness*: planning for the future is more difficult in the face of unresolved uncertainties. Second, it may facilitate *psychological preparedness*: "when resolution of uncertainty is delayed, psychological considerations such as anxiety, anticipation, dread, hope, and impatience are relevant; knowing what the future will bring may permit psychological preparedness, even if nothing can be done to affect this future" (Wu 1999, p. 160).

Heckerling and Verp highlighted the importance of uncertainty aversion in a comparative study of two antenatal screening tests for pregnant women: amniocentesis and chorionic villus sampling. They calculated the expected utility of both tests, based on probabilities and utilities obtained from the literature (e.g. of spontaneous abortion, therapeutic abortion, chromosomal abnormalities, indeterminate results). The expected utility of amniocentesis, which is a second-trimester test, exceeded that of chorionic villus sampling, which is a first-trimester test. However, the delay involved in the second-trimester test carries a burden of increased anxiety that can be high (Robinson, Garner et al. 1988). When this is taken into account chorionic villus sampling may become the procedure of choice: "The utilities of all outcomes occurring after the results of amniocentesis become available, may be diminished by a 'cost of anxiety' from having to wait until the second trimester for these results…. The expected utility of amniocentesis was quite sensitive to this cost, decreasing sharply as the cost of anxiety increased. For a cost of anxiety greater than 0.1 utility unit [on a scale of 0 to 100], chorionic villus sampling would be preferred; for a cost of less than 0.1 unit, amniocentesis would be preferred" (Heckerling and Verp 1991, pp. 664-665).

Again, due to lack of relevant data, it is uncertain whether Australians would be willing to pay, or would accept less spending on other health services, to avoid the delayed resolution of uncertainty in connection with a medical treatment – that is, whether they would be prepared to trade-off other social benefits to avoid uncertainty during the pre-outcome period, independently of any net health gain. As Wu notes: "it is quite reasonable for sufferers of anxiety to pay something to avoid suffering anxiety and its emotional and physical consequences: sleepless

nights, lack of concentration, loss of productivity, excessive impatience and irritability, etc" (Wu 1999, pp. 188-189). This bears on the more general question whether the public believes the objective of a publicly funded health system should be to improve population health alone, or whether it should be to increase "utility" more generally construed, including the avoidance *ex ante* emotions such as anxiety, regret and uncertainty. The lack of attention paid to this issue is surprising since the outcomes of health decisions are typically uncertain and present considerable scope for reassurance and regret.

Table 15. Studies Relevant to The Ex Ante/Ex Post Distinction in Health Care

Study	Country	Number of Subjects	Type of Subjects	Elicitation Method
(Cook, Richardson et al. 1994)	Australia	553	Patients	TTO[a]
(Smith 1996)	Australia	16	Patients/GenPop[b]	TTO
(Ryan 1998)	UK	1048	Patients	WTP[c]
(Salkeld, Ryan et al. 2000)	Australia	600	GenPop[c]	DCM[d]

a   TTO = Time Trade-Off
b   GenPop = General Population
c   WTP = Willingness to Pay
d   DCM = Discrete Choice Method

SOME CORROBORATING EVIDENCE

In the standard economic model, people are assumed to be basically self-interested. As a consequence, concerns for fairness play no role in explaining behaviour, or are seriously marginalised. "This nonfairness assumption expresses a resistance to explanations of economic actions in moral terms that has deep roots in the history of the discipline" (Kahneman, Knetsch et al. 1986b, p. S286). Among "true believers" in the standard economic model, "any appearance of concern for values of fairness or for the welfare of strangers is interpreted in terms of self-interest and strategic behavior" (Kahneman, Knetsch et al. 1986b, p. S286). Cases of apparently fair behaviour are either interpreted within the dominant economic paradigm as evidence of irrationality, or are treated as "isolated phemonena of little economic significance" (Kahneman, Knetsch et al. 1986b, p. S286).

In the present section we consider some experimental evidence from bargaining and market games that highlights fairness as a motivation in social interactions. Of course, human beings are complex, and a concern for others does not preclude a concern for self. People are neither completely selfish nor completely altruistic. As Thaler observes, "most people prefer more money to less, like to be treated fairly, and like to treat others fairly. To the extent that these objectives are contradictory, subjects make trade-offs…. Future research should investigate the factors that produce each kind of behavior, rather than attempt to demonstrate that one type of behavior or the other predominates" (Thaler 1988, p. 205). The experimental evidence examined in this section provides further evidence that the neglect of equity issues in QALY-based CEA is potentially a serious defect.

Ultimatum Games

Ultimatum games are a particularly simple type of bargaining game. Typically they involve two players who are unknown to each other. Player 1 (the "allocator" or "proposer") is given an initial sum of money and asked to divide it between himself or herself and player 2 (the "recipient" or

"responder"). If player 2 accepts the "offer" it is theirs to keep, and player 1 retains the balance, at which point the game ends. If player 2 rejects the offer neither player recieves anything, and the game ends. Game theory prescribes only two "rational" solutions to this game, both of which give player 1 virtually all the money. More precisely, game theory combined with the assumption that players are expected utility maximisers, and that utility is measured by monetary payoffs, prescribes these two solutions. First, on the assumption that player 2 would reject a zero offer, player 1 should offer player 2 the smallest positive amount possible, for example one cent, and player 2 should accept it because even the smallest offer is better than nothing. Alternatively, on the assumption that player 2 would not reject a zero offer, player 1 should offer player 2 nothing, and player 2 should accept it. These two combinations of strategies – player 1 offers the smallest positive amount and player 2 accepts, player 1 offers nothing and player 2 accepts – place the players in "strategic equilibrium": neither player can gain by unilaterally switching to another strategy, if the other player maintains his or her strategy.

In real life, however, this is typically not the way the game proceeds. Player 2 may be insulted by an initial low offer, it may strike them as unfair, or an abuse of power, or as lacking generosity or charity. In short, player 2 may reject a low offer, even at his or her own expense, and player 1 is aware of this. As a result, a fairer division of the initial endowment results in practice than a cold strategic analysis would suggest. It must be kept in mind that subjects in bargaining experiments typically receive payment for their participation based on the amount they make in the bargaining game. So the exercise is not just of theoretical interest to those taking part.

One of the earliest experiments using ultimatum games was conducted by Güth, Schmittberger and Schwarze among economics students (Güth, Schmittberger et al. 1982). The results of 21 ultimatum games (listed alphabetically from A to U) are given in Table 16. The second column gives the amount to be distributed, c, ranging from 4 to 10 deutsche marks (DM); the third column gives the amount player 1 elected to keep; and the fourth column indicates whether player 2 accepted (1) or rejected (0) the offer. It can be seen that player 1 did not always offer the minimum, and that player 2 did not always accept the offer. The mean offer was in fact 37 per cent of c. When the experiment was replicated a week later, those in the role of player 1 made lower offers (mean 32 per cent of c), but this also resulted in a greater number of rejections (see Table 17.) The decision of player 2 to reject an offer was positively correlated both with a low payoff in absolute terms, and a small share of the initial endowment.

In a third experiment, subjects were told they would play both roles in separate games, and were asked to specify the minimum they would accept as player 2. This allows some insight into the complete acceptance/rejection strategy of player 2, not only his or her reaction to player 1's specific offer. The median "reservation demand", which was actually used to determine payoffs to subjects in the role of player 2, was DM2.50 out of an initial endowment of DM7.00. When the games were played the mean offer by subjects in the role of player 1 was a generous 45 per cent of the initial endowment. As the authors conclude, in making their choices those in the role of player 2 "rely on what they consider a fair or justified result …, and do not hesitate to punish if their opponent asks for 'too much'" (Güth, Schmittberger et al. 1982, p. 385). Knowing this, allocators make reasonable offers.

Kahneman, Knetsch and Thaler replicated the study by Güth, Schmittberger and Schwarze, but took added precautions to ensure that subjects understood the payoffs clearly. They did this by asking subjects preliminary diagnostic questions, which resulted in 22 subjects being dropped,

Table 16. Naïve Decision Behavior in Easy Games

Game	c – Amount to be distributed	Demand of player 1 (DM)	Decision of player 2
A	10	6.00	1
B	9	8.00	1
C	8	4.00	1
D	4	2.00	1
E	5	3.50	1
F	6	3.00	1
G	7	3.50	1
H	10	5.00	1
I	10	5.00	1
J	9	5.00	1
K	9	5.55	1
L	8	4.35	1
M	8	5.00	1
N	7	5.00	1
O	7	5.85	1
P	6	4.00	1
Q	6	4.80	0
R	5	2.50	1
S	5	3.00	1
T	4	4.00	0
U	4	4.00	1

Source: (Güth, Schmittberger et al. 1982)

Table 17. Experienced Decision Behavior in Easy Games

Game	c – Amount to be distributed	Demand of player 1 (DM)	Decision of player 2
A	10	7.00	1
B	10	7.50	1
C	9	4.50	1
D	9	6.00	1
E	8	5.00	1
F	8	7.00	1
G	7	4.00	1
H	7	5.00	1
I	4	3.00	0
J	4	3.00	0
K	5	4.99	0
L	5	3.00	1
M	6	5.00	0
N	6	3.80	1
O	10	6.00	1
P	9	4.50	1
Q	8	6.50	1
R	7	4.00	0
S	6	3.00	1
T	5	4.00	0
U	4	3.00	1

Source: (Güth, Schmittberger et al. 1982)

and by asking subjects to specify their reservation demand by answering a series of yes/no questions, rather than by stating it directly. (This was done in the belief that a series of yes/no questions is easier for subjects to answer (Kahneman, Knetsch et al. 1990)). The results of these games, starting with an initial endowment of $10, are given in table 18. The mean amount offered ranged from $4.21 to $4.76, and in keeping with the previous study, "the actual allocations were quite generous" (Kahneman, Knetsch et al. 1986b, p. S290).

Table 18. Experiment 1 Results

	Class		
	Psychology/ Psychology	Psychology /Commerce	Commerce/ Psychology
Mean amount offered ($)	4.76	4.47	4.21
Equal split offers (%)	81	78	63
Mean of minimum acceptable ($)	2.59	2.24	2.00
Demands > $1.50 (%)	58	59	51
Participants (*N*)	43	37	35

Source: (Kahneman, Knetsch et al. 1986b)

Note: Data presented are by subsample; the results do not include 22 subjects whose answers to the test questions indicated a misunderstanding of the questions.

Binmore, Shaked et al. also repeated the study by Güth and colleagues, but changed it from a one-period ultimatum game to a two-period bargaining game (Binmore, Shaked et al. 1985). The first period was similar to the ultimatum game investigated by Güth and colleagues, with an initial endowment of 100 pence. In the second period the "pie" was reduced to 25 pence, and player 2 assumed the role of allocator. The reduction of the pie constituted, in effect, a penalty for delayed agreement. In period two, player 2 can offer player 1 a penny, and retain 24 pence for himself or herself, without any danger of retaliation. Hence, on game-theory assumptions, player 1 should offer player 2 the smallest amount above 24 pence in period one – that is, 25 pence. In defiance of this logic, when the game was played, the same tendency to "play fair" observed by Güth and colleagues was evident.

In another twist, Binmore, Shaked et al. invited those in the role of player 2 to play again, this time as player 1. The results in this second game were different. The most frequent offer in the first game was 50 pence, but in the second this had fallen to just below 25 pence in keeping with game-theoretic expectations. The authors conclude that once people understand the payoffs clearly, their initial tendency to "play fair" is replaced by "calculations of strategic advantage" (Binmore, Shaked et al. 1985, p. 1180). However, Thaler points outs several aspects of this experiment that might have biased the results. Most importantly, Binmore, Shaked et al. explicitly instructed subjects to maximise their winnings: "How do we want you to play? You will be doing us a favour if you simply set out to maximise your winnings" (quoted in Thaler 1988, p. 199). Implicitly, subjects were told *not* to "play fair" (if this reduced their winnings) even if this was their preference. Even so, most subjects in the first game elected to keep only 50 per cent of the endowment for themselves.

Neelin, Sonnenschein and Spiegel extended these experiments to multi-stage games (Neelin, Sonnenschein et al. 1988). For example, they conducted an experiment with undergraduate economics students using 2-period, 3-period and 5-period games. The final period of any such game is an ultimatum sub-game. The initial endowment was $5.00, which decreased in subsequent periods. For example, in the 3-period game the pie was successively $5.00, $2.50, and $1.25. Players swaped roles in successive rounds. Using "backward induction" it is possible

to calculate what each player should do if they are rational and self-interested. Based on the experimental set-up, in each of the 2-period, 3-period and 5-period games, player 1 should offer $1.25, and player 2 should accept it.[1] However, the authors observed significant deviations from this game-theoretic solution, and differences between the results of the 2-period, 3-period and 5-period games. In the 2-period game allocators and recipients behaved roughly as game theory predicts. Thirty-three out of 40 allocators made offers between $1.25 and $1.50, and only 2 offered an even split ($2.50 each). (These results are similar to those obtained by Binmore, Shaked et al. in their two-game experiment.) However, in the 3-period game only 3 allocators made offers between $1.25 and $1.50, and 28 offered an even split. The results of the 5-period game were different again. Thirty-three allocators made offers between $1.50 and $2.00, and only two offered an even split. The authors note that allocators seem to have adopted the strategy of offering the amount to be played for in period two: "They always act as if they were in the two-round game" (Neelin, Sonnenschein et al. 1988, p. 827). It is possible that multi-stage, alternating-offer bargaining games are too demanding for average players, and that this explains the "myopic" tendency to look no further than the second period (Binmore, Shaked et al. 1988, p. 837; Thaler 1988, p. 201; Guth and Tietz 1990, pp. 437-8).

Taking this multi-stage approach a step further, Weg, Rapoport et al. experimented with games having *no* announced upper bound for the number of rounds. The authors explain the experimentally observed results of such "infinite horizon" games by appeal to notions of equity and equality, again rejecting the hypothesis that players are exclusively concerned with maximising their monetary payoff (Weg, Rapoport et al. 1990). However, due to their complexity, it is difficult to draw reliable conclusions from multi-stage (*n* > 2) alternating-offer games.

In another variation of the ultimatum game, Ochs and Roth conducted an experiment using 2- and 3-period games, but where the reduction in the endowment in successive periods differed for each player (Ochs and Roth 1989). This resulted in a 4 × 2 experimental design with 8 "cells". The rate of pay for participation depended (inter alia) on the discount rate, which was known to each player in advance, and the period in which agreement was reached. Participants played 10 consecutive games against different opponents, which allowed a test of whether subjects learned to bargain for their own advantage. The results were again at odds with the expectations of game theory: "the subgame-perfect equilibrium offer is generally a very poor predictor of the observed outcomes" (Ochs and Roth 1989, p. 361). For example, as in previous studies, there was a high proportion of 50-50 offers in the first round (Ochs and Roth 1989, p. 374). Moreover, although agreement should always be reached in the first period of multi-period games, on the assumption that subjects are rational and self-interested, agreement failed to be reached in the first period in 16 per cent of bargaining rounds. Finally, if player 2 rejects a proposal, he or she should make a counterproposal that is no less than the proposal he or she rejected. However, in 81 per cent of cases player 2 demanded less cash than had been offered by player 1 in the first period. The authors did not put this down simply to confusion: "when player 2 rejects player 1's offer and makes the kind of disadvantageous counterproposal we observe so frequently, we know by revealed preference that player 2's utility is *not* measured by his monetary payoff" (Ochs and Roth 1989, p. 362). This is supported by Bolton: "Note that no amount of incomplete information will explain this: when subjects make disadvantageous counteroffers, they have sufficient information to know that they are turning down money" (Bolton 1991, 1105). Nor did these tendencies change from game 1 to game 10 - that is, as a result of learning.

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1. The reasoning proceeds as follows for the 3-period game. "If play continues to the last round the first party can obtain $1.25 … and the second party, if that person is rational, must accept this division. Therefore, in the second round, the second party must offer at least $1.25 to the first. So, if play continues to the second round the second party will get $1.25 ($2.50 - $1.25). Hence in the first round, the first party must offer $1.25 to the second, which leaves the first party with $3.75 ($5.00 - $1.25)" (Neelin, Sonnenschein et al. 1988, p. 825).

Bolton conducted a series of 2-period ultimatum games in which he got similar results to these earlier studies (Bolton 1991). He explains these results by speculating that participants have preferences over both "absolute" and "relative" money. Absolute money is the cash payoff, and is usually assumed to be the sole measure of players' utility. Relative money is a measure of the *disparity* between the cash payoffs to the two players. "Although cash is the only commodity involved in the negotiations, bargainers act as if there are two: absolute and relative money" (Bolton 1991, p. 1109). According to Bolton, players find absolute and relative money commensurable, and are willing to trade-off one against the other, which explains a number of observed regularities in bargaining games. For example, those in the role of player 2 frequently demand less cash than they were offered by player 1 in the first period, as demonstrated by Ochs and Roth (1989, p. 362). Bolton explains such disadvantageous counter-offers by suggesting that "bargainers are trading away absolute money in order to gain relative money" (Bolton 1991, p. 1109). That is, player 2 will gain less cash from a disadvantageous counter-proposal, but will reduce the difference between his or her payoff and the payoff to his or her opponent. Bolton's *comparative model* incorporates distributional concerns into utility functions, as Ochs and Roth suggested should be done.

In an interesting test of the comparative model, Bolton conducted a series of tournament-style ultimatum games. In such a tournament, player 1's payment for participation is determined by the number of points he or she earns *relative to others in the role of player 1,* and similarly for player 2. That is, "a bargainer now shares a payoff pie with his bargaining counterparts, rather than his bargaining partner" (Bolton 1991, p. 1123). The expectation is that, since individuals in the role of player 1 are competing for a fixed prize that diminishes with their ordinal ranking, and similarly for those in the role of player 2, "the way for a bargainer to obtain as large a *relative* slice as possible is to maximize his bargaining earnings" (Bolton 1991, p. 1123). In other words, results in the tournaments should be closer to game-theoretic expectations. In keeping with this expectation, there were fewer disadvantageous counter-offers in the tournaments, and final rejection rates were lower. "The tournaments provide some evidence that behavior can be manipulated by altering a bargainer's comparison group. The data have a competitive look: there are few disadvantageous counteroffers, and in one case, play was almost identical to the standard theory's prediction" (Bolton 1991, p. 1129).

However, Camerer and Thaler point out a limitation in Bolton's comparative model. They note that his model "does not distinguish a distaste for uneven allocations per se from a willingness to punish a player who has behaved unfairly by making an uneven offer" (Camerer and Thaler 1995, p. 214). Whether player 2 rejects an offer *simply* because it is small compared with player 1's demand (and would reject such an offer, for example, if it was selected at random), or because player 1 is perceived as behaving unfairly, is not a relevant distinction on Bolton's account. However, Blount has conducted a series of ultimatum games in which the perceived intention of player 1 was found to be significant (Blount 1995). She found that subjects are less likely to accept a comparatively low offer from another player than from a computer that randomly assigns payoffs. People are prepared to punish others who behave unfairly, even at some expense to themselves, whereas such punishment is pointless in the case of a random device. "People are punishing unfairness, not rejecting inequality" (Camerer and Thaler 1995, p. 214).[2]

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2. The "sense of fairness" is not unique to humans. In a series of experiments de Waal and colleagues observed that brown capuchin monkeys respond negatively to unequal rewards. In one experiment, monkeys in adjoining cages were offered either a piece of cucumber or a grape for doing the same task, the grape being a more attractive reward. Monkeys receiving the "lower pay" often showed their indignation by refusing to return a token to the human experimenter, or by refusing to accept the lesser reward (sometimes throwing it out of the test chamber). This response was exaggerated when one monkey received a grape for doing nothing. These negative reactions to observations of unequal reward for equal effort tend to confirm the evolutionary origins of the "aversion to inequity" (de Waal 1996; Brosnan and de Waal 2003).

The complexity of the motivations governing responses in ultimatum games was confirmed by Kagel, Kim, et al., who changed the experimental set-up in yet another way. They varied the relative value of the winnings for each player, and the information available to the players about the exchange rate. The pie consisted of 100 "chips" that were worth different monetary amounts to each player. In one of the more interesting games, chips were worth 30 cents to player 1 and 10 cents to player 2, both players knew the value of their own chips, but only player 1 knew the value of both player's chips. In this situation, if player 1 is interested in an equal division of the money he or she should offer 75 chips to player 2. However, due to the asymmetric information condition, player 1 can offer 50 chips, secure a proportionately larger payoff for himself or herself, and still *appear* fair (and thus face little risk of rejection). Subjects participated in 10 bargaining periods, and were paid according to their winnings in one period selected at random. Results showed little support for an equal division of the money. The average offer was 46.9 chips over the ten periods, which represented more than a three-to-one income difference in favour of player 1 (Kagel, Kim et al. 1996, p. 105). Rejection rates were very low (8 per cent) because player 2 had no way of knowing that a 50/50 split of the chips was unfair. By contrast, when both players were fully informed of the value of chips to both players, and chips were worth 30 cents to player 1 and 10 cents to player 2, offers and responses changed. Those in the role of player 1 began by dividing the chips equally. However, high rejection rates by player 2 (52 per cent in the first 3 periods) meant that mean offers rose to an average 63.7 per cent by round 10. The authors interpret the results of these experiments as calling into question "an altruistic impulse" towards fairness. However, they are careful not to reject altruism altogether as a motivation in ultimatum games: "we believe that for some subjects at least, *part* of the deviation from subgame perfection in ultimatum games represents 'trying to be fair'" (Kagel, Kim et al. 1996, p. 102). The study shows that, although ultimatum games are simple, the motivations of players are not.

Some characteristics are common to most experiments involving ultimatum games (involving symmetric payoffs and and full information for both players) (Bolton 1991; Fehr and Schmidt 1999). (i) Mean opening offers deviate from perfect equilibrium in the direction of equality: most offers fall within the range of 40 to 50 per cent of the endowment. (ii) Player 1 tends to receive more than player 2 as a result of a first-mover advantage. (iii) Very few initial offers are for less than 20 per cent. (iv) Low offers are often rejected. (v) Rejected initial offers are often followed by disadvantageous counter-proposals: player 2 may make a counter-proposal that leaves him or her with less than the offer he or she rejected. It is worth noting that these findings do not seem to vary with the size of the initial endowment – that is, allocators continue to "play fair", though there is some evidence that as the stakes are raised fewer offers are rejected (Forsythe, Horowitz et al. 1994; Camerer and Thaler 1995; Slonim and Roth 1998; Cameron 1999). Moreover, Roth, Prasnikar, et al. observed between-country variations in the tendency to reject low offers: countries where low offers are observed do not have higher disagreement rates (Roth, Prasnikar et al. 1991, p. 1070). Conclusions (i), (iii), (iv) and (v) contradict the assumption that people are exclusively concerned with their own material well-being, and do not care about fairness in social interactions: "experimentally observed ultimatum bargaining behavior clearly contradicts the most obvious rationality requirements of game theory and also of economic theory" (Guth and Tietz 1990, p. 446).

The results of the preceding bargaining games, involving real monetary payoffs, suggest that people are not concerned exclusively with their own material well-being. Some apparently "fair" behaviour observable in these games can be explained by confusion on the part of players, or as an artifact of "bounded rationality", but a residual body of decision data remains that resists this explanation. "Experimentally observed ultimatum bargaining behavior reveals how considerations of distributive justice seriously destroy the prospects of exploiting strategic power" (Guth and Tietz 1990, p. 446). These experiments suggest that people are willing to be fair, and to punish

others who are not willing to be fair, even at some cost to themselves: "people are willing to sacrifice considerable monetary amounts in order to punish someone who has been too greedy and … they do so even if it will not be of any help for them in the future" (Guth and Tietz 1990, p. 447). This does not impugn game theory as a theoretical discipline, or game theory combined with expected utility theory, nor does it call into question the relevance of these disciplines for economics. As in the physical sciences, abstract models can facilitate insights, promote precision, and lead to novel predictions. Rather, these experimental results show the limitations of game theory and expected utility theory as predictors of real behaviour. "While the problem of developing descriptively powerful theory for games of this sort does not call for anything like the wholesale abandonment of the apparatus of game theory, neither is it likely that game-theoretic analysis unaided by empirical observation will lead to reliable models of behavior" (Roth, Prasnikar et al. 1991, p. 1094).

Market Games

Roth, Prasnikar, et al. conducted a series of 2-period ultimatum games in four countries: Israel, Yugoslavia, the USA and Japan (Roth, Prasnikar et al. 1991). For this experiment 10 bargaining sessions were held with different opponents, all prices were translated into units of 1,000 tokens, and offers had to be stated in increments of 5. Player 1 therefore should offer player 2 the smallest increment of five tokens, or nothing at all. The results, however, were similar to previous studies: in every country initial offers were substantially above the minimum, and there was a substantial number of declined offers which were detrimental to both players. "Equilibrium price proposals (of 0 or 5) make up less than 1 percent of the data from any country. In all countries the price proposals made by bargainers are much nearer the middle of the range, and in all countries low offers are rejected at a substantially higher rate than higher offers" (Roth, Prasnikar et al. 1991, p. 1082).

However, the authors also conducted a series of 1-period market experiments in these four countries, and the results were very different. In the market games each of nine buyers submitted an offer to a seller for an object worth 1,000 tokens to everyone. The seller then has the opportunity to accept or reject the highest offer. If the seller accepts the offer he or she earns the highest price, the highest bidder earns the difference between 1,000 tokens and the price he or she offered, and the other buyers receive nothing. If the seller rejects the highest bid, all players receive nothing. Any buyer who makes a bid for less than 1,000 tokens risks having his or her offer exceeded. In fact, there are two equilibrium offers available to player 1, depending on whether he or she would accept zero: 1,000 tokens or 995 tokens (given that offers had to be in increments of 5) . Conversely, the seller should accept the highest positive offer whatever it is, or gain nothing at all. Whereas outcomes in the ultimatum game differ significantly from equilibrium, in the market game "outcomes converge quickly to the perfect equilibrium, and do not deviate from equilibrium once it has been achieved" (Roth, Prasnikar et al. 1991, p. 1070). In none of the four countries in which the experiment was conducted was the highest bid ever rejected, and in every session the transaction price rose to the equilibrium price of either 995 or 1000.

There are two main explanations for this discrepancy between behaviour in the bargaining context and in the market context. First, it may be that the concerns for fairness that arise in ultimatum games are context-dependent and do not arise in market games. Alternatively, concerns for fairness may arise in both contexts, but players may feel constrained to express these concerns differently in the two contexts. Roth, Prasnikar et al. provide convincing reasons in support of this latter proposal (Roth, Prasnikar et al. 1991). For example, a buyer in the market experiment may believe a bid of 500 tokens is fair, but may feel (reluctantly) pressured into making an equilibrium offer (perhaps after several rounds) to avoid other buyers from benefitting

from less fair offers. Arguably, it is this same desire that greed not be rewarded that prompts players in the ultimatum game to reject low offers. In other words, the same concern for fairness can lead a player away from equilibrium in the ultimatum game and towards equilibrium in the market game. "The point in considering such a hypothetical buyer is to observe that in the market game his nonmonetary preferences cause him to behave in a manner indistinguishable from an income-maximizer, while in the ultimatum game his preferences lead away from the equilibrium predicted for income-maximizers. The difference lies not in the preferences, or in the 'social norms' elicited by the game which these preferences may reflect, but in how such preferences interact in the different games and in the outcome that emerges" (Roth, Prasnikar et al. 1991).

Dictator Games

Ochs and Roth note that much of the data from their own study, as well as from other studies, can be explained by assuming that participants have concerns for the distribution of outcomes, and not only for their own monetary payoff. They are cautious not to claim that players "try to be fair". Players have to estimate the reactions of their opponent. If players believe that their *opponents* have distributional concerns, it may serve their own interests to make "fair" offers. Even players who offer to divide the money equally "may simply have judged the risk of rejection of a more unequal offer to have outweighed the benefits" (Ochs and Roth 1989, p. 379). However, in dictator games there is no possibility of retaliation by the other player, and even in these games "utilities cannot simply be assumed to be equal to the monetary payoffs of the players" (Ochs and Roth 1989, p. 379).

In dictator games player 1 makes a unilateral decision on how to divide the initial endowment. Player 2 then has no option but to accept the offer, and there is no opportunity for retaliation. In this situation player 1 should offer player 2 nothing if he or she is self-interested and rational.

Kahneman, Knetsch and Thaler conducted a two-part experiment in which they first asked subjects to divide $20 with another anonymous participant. Only two possible divisions of the amount were allowed: a 50/50 split, or $18 to self and $2 to the other. The subjects were informed that 8 pairs of students would be selected at random and paid for their participation in the experiment. Even though there was no possibility of rejection or retaliation, a significant majority of the subjects, 76 per cent, chose to divide the money equally. This provides striking evidence "that fair allocations are observed even under conditions of complete anonymity and with no possibility of retaliation" (Kahneman, Knetsch et al. 1986b, p. S291). In the second part of the experiment the authors matched each subject with two anonymous participants from the first part who had not received payment for their participation. One of these two participants had behaved "selfishly" and kept $18 for himself or herself, the other had behaved "fairly" and divided the money evenly. Subjects were asked to make a choice: they could either divide $12 evenly with the "selfish" individual ($6 each), or divide $10 evenly with the "fair" individual ($5 each). This provided another test of whether people are willing to undergo a personal loss to punish unfair behaviour, or reward fair behaviour, by anonymous third parties. Of those taking part in the experiment, 74 per cent paid $1 to punish the "greedy" individual and simultaneously reward the "generous" individual. In a separate experiment the authors repeated the second part of this experiment with different subjects, and found that an even more impressive 81 per cent would prefer to split $10 evenly with a "fair" allocator than split $12 evenly with a "selfish" individual.

Forsythe, Horowitz et al. conducted an experiment in which they compared ultimatum games with dictator games (Forsythe, Horowitz et al. 1994). Their primary aim was to test whether the results of ultimatum games can be explained solely by participants' concern with fairness (the "fairness hypothesis"). If fairness is solely responsible for players' behaviour, the distribution of offers in

the two games should not differ. On the contrary, however, the authors found that when participants are paid according to their winnings in these games, "players are more generous in the ultimatum game than in the dictator game" (Forsythe, Horowitz et al. 1994, p. 357). This is shown in figure 1, which pools the results from two series of ultimatum and dictator games held several months apart, using an initial endowment of $5. It can be seen that in the dictator game

Figure 1. Dictator with pay (pooled) vs ultimatum with pay (pooled).
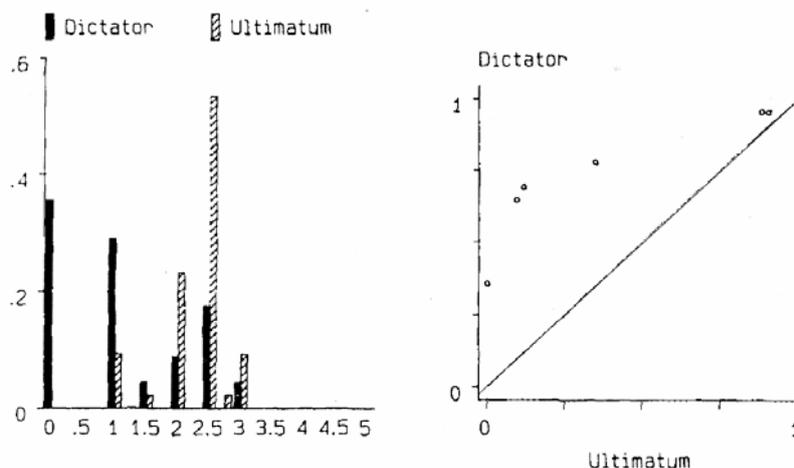
Source: (Forsythe, Horowitz et al. 1994)

36 per cent of players offered nothing, whereas in the ultimatum game 65 per cent offered to split the money equally. At most, however, this shows that behaviour in ultimatum games cannot be explained *solely* by participants' concern with fairness. This is compatible with the hypothesis that participants are motived both by self-interest and by a desire to "play fair", and trade-off one against the other depending on variables that are not well-understood. This is supported by the fact that, while 36 per cent of players in the dictator game offered nothing, 22 per cent offered an equal split *despite there being no possibility of retaliation*. It seems reasonable to conclude that players in the ultimatum game make non-trivial offers partly because they fear rejection of their offer (are self-interested), but also partly out of a sense of fairness.

THE PUBLIC'S VIEWS ON PUBLIC PARTICIPATION

An underlying assumption of the empirical studies examined in this review is that the public has a legitimate role to play in setting health-care priorities. There are arguments for and against such public involvement, raising complex issues involving the importance of democratic procedures, lack of public knowledge, the costs of participation, and so on. However, a number of studies have consulted the public on their role in setting health-care priorities, and the evidence suggests that the public does want a say in how priorities are set in the health sector, though the level of decision making they are being asked to participate in has a bearing on willingness to participate, as does the amount of time and effort they are being asked to put in.

Using a mail questionnaire, Richardson, Charny et al. asked members of the public in England for their opinions on health services, including whether they are in favour of greater public involvement in health care decision making (Richardson, Charny et al. 1992). Table 19 shows that the respondents were indeed in favour of greater public involvement in such decision making. A majority of respondents, 65 per cent, agreed with the statement that, "the public should have

more of a say in making the decisions." Supporting this, 89 per cent thought that the health authority should give people more information about what it does, and 93 per cent thought that the health authority should provide more information about the services it provides. The authors conclude that "[p]ublic support for the delegation of decision making to professionals and the health authority cannot be assumed" (Richardson, Charny et al. 1992, p. 681).

Table 19. Views of 690 Respondents on Statements about Decision Making and Running of Health Service. Figures are Numbers (Percentages)

Statement	Agree	No opinion	Disagree
Decisions should be left to the doctors and other experts at the health authority	400 (58)	23 (3)	268 (39)
The public should have more of a say in making the decisions	446 (65)	49 (7)	188 (27)
Local people are not able to influence the decisions	471 (68)	63 (9)	154 (22)

Source: (Richardson, Charny et al. 1992)

In another British study, Bowling, Jacobson et al. asked members of the public whether they thought that surveys of the public's opinions, like the one they were conducting, should be used in the planning of health services (Bowling, Jacobson et al. 1993). Seventy-one per cent said "yes". Similarly, 77 per cent of the doctors surveyed thought that surveys of doctor's opinions and priority rankings, like the one they were conducting, should be used in the planning of health services.

In a subsequent study, Bowling asked 2005 members of the public who they thought should set health care priorities (Bowling 1996). Subjects were asked to select their answer from five listed possibilities. The results are given in Table 20. A majority of respondents, 56 per cent, favoured doctors at local level, while 17 per cent chose "the public at local level." Only 3 per cent chose "politicians and the government at local level." It is not clear, however, whether participants in this study distinguished clearly between *budget level* decisions and *bedside level* decisions (Nord 1999a, pp. 7-8). Arguably, the training, expertise, and experience of doctors is more relevant in

Table 20. Percentage Choosing Different Groups

| Responsible group	Percentage (Numbers)
Doctors at local level	56 (1104)
Local health authorities	19 (377)
The public at local level	17 (336)
Local NHS managers	5 (89)
Politicians and the government at local level	3 (61)

Source: (Bowling 1996)

the latter context. Confirming the important role the public believes doctors should play in health care rationing, 75 per cent of respondents either agreed or strongly agreed with the following statement (which does not mention public participation in priority setting): "The responsibility to ration health care spending should rest with the doctor rather than a hospital manager, health authority, politician, or government minister." Subjects in this study nevertheless saw an important role for the public in priority setting. As in the 1993 study, subjects were asked whether "surveys of the general public, like this one, should be used in the planning of health services." A

clear majority, 88 per cent, agreed, while 7 percent disagreed, and 5 per cent said they did not know.

Abelson, Lomas, et al. conducted a study in Canada that probed more deeply into the extent of the public's willingness to be involved in local health-care and social-service decision making (Abelson, Lomas et al. 1995). They surveyed five groups: randomly selected citizens, interested citizens who attended a town-hall meeting, appointees to district health councils, elected council officials, and experts in health care and social services. They sought to elicit informed views from these groups by using "deliberative polling", which allowed group discussions of the topics under review. Of those surveyed, 82.4 per cent expressed a personal willingness to take a consulting role in health-care and social-service decision making, and 71.9 per cent were

Figure 2. Percentage of people polled who were personally willing to take on roles in overall decision making and responsibility for specific areas of decision making in health and social services in their communities (screened bars). Black bars represent the percentage of those polled who thought that their group was suited to taking on these roles and responsibilities
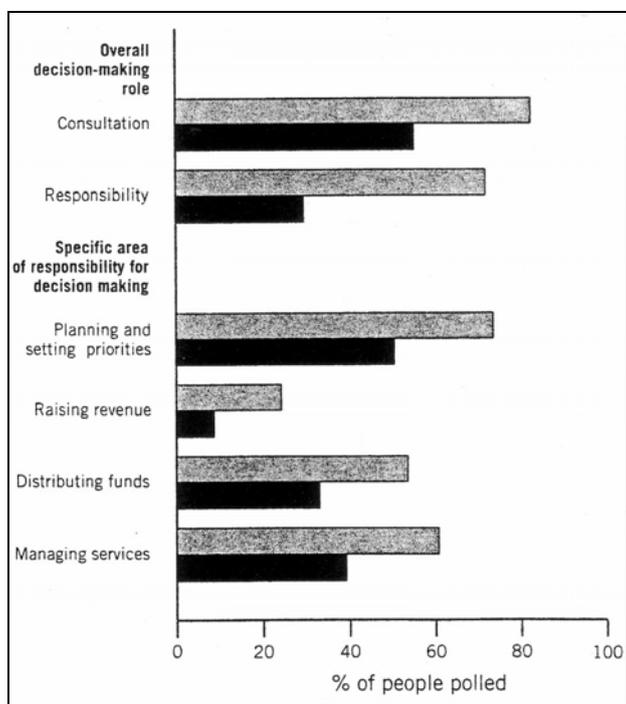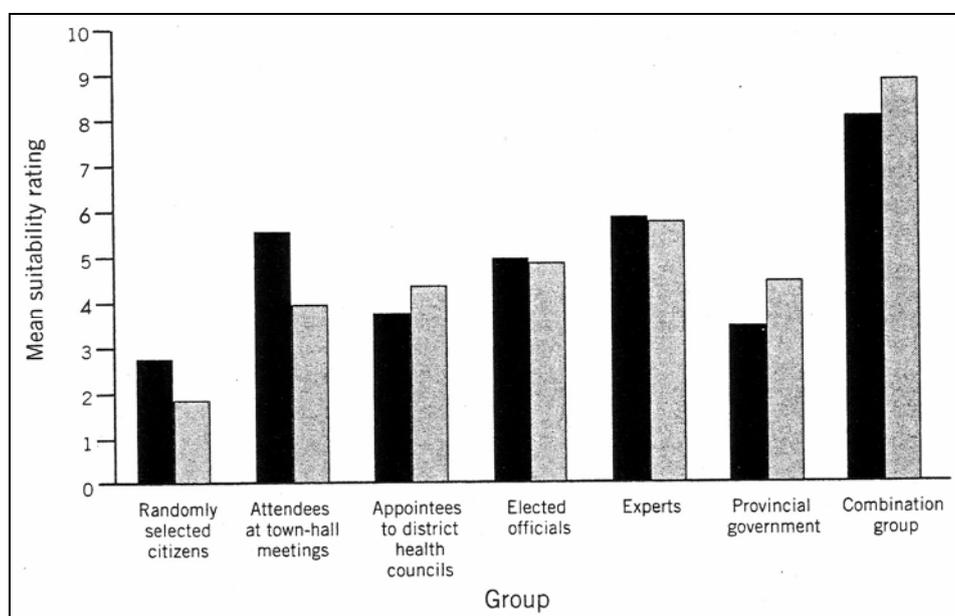

Source: (Abelson, Lomas et al. 1995)

personally willing to take responsibility for such decisions making (see Figure 2). Elected officials were most willing to take responsibility (84.8 per cent), and randomly selected citizens least willing (60.5 per cent). Not surprisingly, "[r]andomly selected citizens and town-hall attendees were more interested in taking a consulting role than a responsibility role" (Abelson, Lomas et al. 1995, p. 407). The percentage of elected officials who thought *their group* should be responsible for health-care and social-service decision making fell to 50 per cent, and only 17.4 per cent of randomly selected citizens agreed that their group was suitable for this role. "[P]eople are much more willing to be personally involved in decision making than to have their group involved" (Abelson, Lomas et al. 1995, p. 410). Subjects expressed more or less willingness to be involved in health-care and social-service decision making depending on the specific role. For example, there was a greater willingness among participants to assume responsibility for planning and setting priorities than for raising revenue, distributing funds, or managing services (Figure 2). As the authors note: "Our results go beyond those of other studies to suggest that,

although the public is willing to be involved in planning and setting priorities, it may be willing to take on only a limited consulting role. Our results also show an almost unanimous lack of willingness to take on the raising of revenue – an activity that involves the total size of the budget and figuring out the sources of funding" (Abelson, Lomas et al. 1995, p. 411).

Participants in this study were also asked to rate seven groups in terms of their suitability to take sole responsibility for health-care and social-service decision making. The five groups included those taking part in the study, plus provincial government, and a combination group. The results are given in Figure 3, and show that participants overwhelmingly favour some form of combined decision-making body, with no one group being given sole responsibility for health-care and

Figure 3. Change in the mean ranking of suitability of groups to take on sole responsibility for all local decision making in health care and social services. Black bars show the mean ranking of groups by people polled before meetings to discuss devolved decision making; screened bars show rankings given after the meetings. There was a statistically significant (p < 0.01) change in the rankings of all groups except elected officials and experts.

Source: (Abelson, Lomas et al. 1995)

social-service decision making. Randomly selected citizens attracted the lowest rating as sole decision-making group. Support for randomly selected citizens and attendees at town-hall meetings in fact decreased as a result of discussion. "[D]uring the 2-hour meeting, as information was presented and elements of a complex decision-making process were described and discussed, participants became less willing to accept these responsibilities and more willing to assign them to traditional decision makers" (Abelson, Lomas et al. 1995, p. 410). When asked which groups should be represented on a combined decision-making body, experts were ranked first (chosen by 82.5 per cent of respondents), town-hall meeting attendees ranked second (chosen by 74.2 per cent), and randomly selected citizens ranked last (chosen by 39.2 per cent). The relatively low ranking given to randomly selected citizens is, of course, consistent with the higher ranking given to "interested citizens", and with the general willingness across all groups to be involved in health-care and social-service decision making, particularly on a consultancy basis. Finally, all five groups taking part in the study thought that information about needs was most important for health-care and social-service decision making. With the exception of elected

officials, all groups thought that information about benefits was next in importance, followed by costs, and finally preferences. Elected officials ranked costs second.

In a study conducted in Finland, Myllykangas, Ryynänen et al. survey doctors, nurses, politicians and the public on their views concerning priority setting in the health area (Myllykangas, Ryynänen et al. 1996). Among other things, subjects were asked whether they agreed, disagreed, or had no opinion about the following statements:

> Politicians should decide who will be treated and who will not.
> All prioritisation decisions should be made by doctors.

An overwhelming majority disagreed with the first statement: 99 per cent, 93 per cent, 96 per cent, and 97 per cent, respectively, of nurses, doctors, politicians, and the general public. Responses to the second statement were more mixed, but with 77 per cent, 93 per cent, 95 per cent and 79 per cent, respectively, of nurses, doctors, politicians, and the general public, agreeing with the statement. The results of this study are hard to interpret, however, in light of the fact that no distinction was made between different levels of decision making. It is possible, for example, that 93 per cent of doctors would not agree that they should make allocation decisions *at the budget level.* Interestingly, this study detected widely divergent views between these groups on some issues. For example, only 14 per cent of doctors agreed with the statement, "Rich people should pay for their treatment", whereas 69 per cent of the general public agreed. The authors conclude: "If prioritisation was left entirely to doctors, health care provision would not reflect the views of other groups in some important ways" (Myllykangas, Ryynänen et al. 1996, p. 212).

Litva, Coast et al. conducted a study in the UK to test the degree of support for public involvement in health care decision-making (Litva, Coast et al. 2002). Informants were drawn from the general public as well as from health and non-health-related organisations. Like the study by Abelson, Lomas, and colleagues, this one sought to test the degree of support for public involvement in health care decision-making at different levels: specifically, at the health system level, the programme level, and the individual patient level. At the health system level subjects were asked:

> The Health Authority can provide either one very well equipped casualty department or have basic emergency care at two hospitals. Would you want the public involved in deciding which service will be funded?

At the programme level subjects were asked:

> The Health Authority has enough money to fund either a new cancer ward or a new mental health ward. Would you want the public involved in deciding which programme receives the funding?

At the individual level subjects were asked:

> Two people require an expensive and effective drug treatment but the health authority only has the money to fund one patient. Would you want the public involved in the decision about which patient gets the medication?

The results are given in Table 21. They show most support for public participation at the system level, less support at the programme level, and least support at the individual patient level. Confirming the findings in the study by Abelson, Lomas et al., it emerged from the focus groups

and interviews that, although there was strong support for public consultation at the system level, it was felt that the public should not be responsible for making decisions. The views of the public should be heard and valued - they should inform decision-making - but the final decision should lay with the relevant professionals. The authors conclude: "Two issues are found in all [focus] groups and at all decision-levels: the need for information and to take account of public experience and emotions" (Litva, Coast et al. 2002, p. 1834).

Table 21. Willingness of the Public to be Involved in Decision-making

Type of decision	Agreement to public involvement *n* (%)			
	Yes	No	Unsure	No answer
System level	39 (68)	4 (7)	9 (16)	5 (9)
Programme level	29 (51)	15 (26)	4 (7)	9 (16)
Patient level	12 (21)	30 (53)	7 (12)	8 (14)

Source: (Litva, Coast et al. 2002)

In an Australian study, Wiseman, Mooney and colleagues surveyed the general population about whether their preferences should be used to inform priority-setting decisions (Wiseman, Mooney et al. 2003). Like the studies by Abelson, Lomas et al., and Litva, Coast et al., this one explicitly distinguished between different levels of priority setting in health care. Subjects were asked whether their preferences should play a role in allocating resources between health care programmes, between medical procedures, and at a global level. To aid understanding, participants were given examples of priority setting at each level. The results are shown in Table 22. They indicate that "the majority of citizens expressed a strong preference for using public preferences of the general public to inform priority-setting decisions in health care" across all three levels (Wiseman, Mooney et al. 2003, p. 1004). Participants were also asked whether the preferences of other groups should play a role in setting health-care priorities. Confirming the 1996 study by Bowling, and the study by Litva, Coast et al., doctors were most frequently given the highest ranking of 1 across all three levels (see Table 23). Members of the general public received the third greatest number of nominations for priority setting across population groups, and the fourth greatest number of nominations for priority setting across health-care programmes and medical procedures. The authors report that "a substantial number of respondents ranked the preferences of citizens above those of doctors" (Wiseman, Mooney et al. 2003, p. 1005). This was 35 per cent for priority setting across health care programmes, 36 per cent for priority setting across medical procedures, and 41 per cent for priority setting across population groups. Another important fact to emerge from this study is that "the vast majority (97%) felt that priority-setting decisions should be informed by the preferences of more than one group" (Wiseman, Mooney et al. 2003, p. 1005).

Table 22. Use of Public Preferences to Inform Priority Setting

Public preference	Percentage distribution by level of priority setting		
	Priority setting across health care programs	Priority setting across medical procedures	Priority setting across population groups
Yes	78.0	74.0	77.2
No	12.1	19.3	14.5
Missing	9.9	6.7	8.3
Total (*n* = 373)	100.0	100.0	100.0

Source: (Wiseman, Mooney et al. 2003)

Table 23. Groups Identified by Citizens to be Involved in Priority Setting in Health Care

| | Percentage distribution | | | | | |
| | Setting priorities across health care programs (level 1) | | Setting priorities across medical interventions (level 2) | | Setting priorities across population groups (level 3) | |
Group	Most important	Not at all important	Most important	Not at all important	Most important	Not at all important
Doctors	40.5	3.5	47.5	3.0	33.2	3.6
Managers of health Services	21.6	5.9	21.0	4.6	26.3	5.7
Patients and their Families	18.1	8.1	16.0	8.8	14.5	9.8
General public	13.5	10.1	10.0	12.6	18.4	10.3
Politicians	3.1	19.6	2.9	19.7	4.2	19.1
Other	3.3	53.0	2.6	51.3	3.4	51.5
Total	100.0	100.0	100.0	100.0	100.0	100.0
(Sample size)*	(*n* = 393)	(*n* = 547)	(*n* = 381)	(*n* = 604)	(*n* = 380)	(*n* = 592)

Source: (Wiseman, Mooney et al. 2003)

* This figure represents the total number of times each group were nominated and sums to more than the number of individual respondents (i.e. 373) because some people nominated more than one group.

In another Australian study, Richardson obtained results suggesting that citizens may sometimes want to abdicate responsibility for health care decisions, and prefer for them to be made by governments. Richardson dubbed this the "Abdication Hypothesis" (Richardson 2002c, p. 671), and tested it in the context of time discounting. Subjects were asked to assume the role of a government committee member and to consider a programme that would save "a large number

Table 24. In general, should governments override public opinion?

| | Benefits received in: | |
General principle	10 years (% yes)	20 years (% yes)
a) Even if the government believes the public is being short sighted, it should follow public opinion and spend exactly what the public wants on saving lives in the future.	26	22
b) If the government believes the public is being short sighted, it should compromise and spend more than the public wants but less than they believe to be right, on saving lives in the future.	36	40
c) If the government believes the public is being short sighted, it should take no notice of public opinion and do what it believes is right.	38	38
Total	100	100
N	50	45

Source: (Richardson 2002c)

of lives". The programme was described as having strong public support *if the benefits occurred immediately*. However, the lives saved are in the future, and subjects were told that people do not want to pay taxes now for a programme that will help people in X years time. "X" was replaced by "10 years" and "20 years" in two different versions of the questionnaire. Richardson found that "a significant majority of respondents (a weighted average of 66% …) were prepared to override public preferences when larger benefits could be obtained in 10 years," but that "only a minority – 35% - were prepared to override public opinion when the benefits were in 20 years"

(Richardson 2002c, p. 671). This suggests that the public's views on public involvement may be sensitive to context. In a follow-up question, Richardson asked participants to indicate which of three statements about government decision-making they supported most. The results are given in Table 24. It can be seen that from 74 per cent (36% + 38%) to 78 per cent (40% + 38%) of respondents supported the overriding of public opinion by government "if the government believes the public is being short sighted". The results of this survey suggest that the degree of public support for public involvement in heath care decisions may be more complex than is usually assumed, and that "the real world citizen may elect to delegate certain decisions" (Richardson 2002c, p. 673).

Table 25. Studies of Paternalism

Study	Country	Number of Subjects	Type of Subjects	Elicitation Method
(Richardson, Charny et al. 1992)	England	704	GenPop[a]	DCM[b]
(Bowling, Jacobson et al. 1993)	Britain	828	GenPop/Doctors	DCM
(Myllykangas, Ryynänen et al. 1996)	Finland	3,830	Nurses/Doctors/Politicians/GenPop	DCM
(Abelson, Lomas et al. 1995)	Canada	280	GenPop/Health Officials	DelPol[c]
(Bowling 1996)	Britain	2005	GenPop	DCM
(Litva, Coast et al. 2002)	Britain	57	GenPop	FG[d]/IDI[e]
(Richardson 2002c)	Australia	78	GenPop	DCM
(Wiseman, Mooney et al. 2003)	Australia	373	GenPop	DCM

a   GenPop = General Population
b   DCM = Discrete Choice Method
c   DelPol = Deliberative Polling
d   FG = Focus Groups
e   IDI = In-Depth Interviews

CONCLUSION

The studies included in this review are of variable quality. They range from high quality representative samples through to opportunistic sampling of unrepresentative groups; some score higher in terms of reliability, validity, and the avoidance of framing effects, while others score lower; some use relatively well-understood elicitation methods, others use more experimental methods; some attempt to quantify preferences, others attempt only to uncover their direction. However, collectively they demonstrate that for a range of issues, such as severity of illness, potential for health improvement, age, and the treatment of costs, there is a divergence between community values and those assumed in health economic evaluations.

Economics is usually defined as the discipline which, *inter alia*, seeks to explain how limited resources can best be used to maximise social welfare. Orthodox welfare theory assumes that social welfare is a function of individual utilities, and that a re-distribution of initial wealth or final income should satisfy concerns about social justice. However, the evidence collected here suggests that, at least in the health sector, people do not have the simple objectives assumed in orthodox welfare theory, and that issues of fairness play a role in the public's evaluation of programmes and services that cannot be accommodated by the mechanism of lump sum re-

distributions of resources before individuals commence "trade", not least of all because many of the assumptions of mainstream economics simply do not apply in the health context (McGuire, Henderson et al. 1988; Rice 1998). In particular, the studies reviewed here decisively show that the assumption of "distributive neutrality" – the assumption that health benefits (QALYs) are valued equally by the community irrespective of their distribution – cannot be sustained. The general populations of the countries in which these studies have been conducted are crucially concerned with social justice, and are prepared to sacrifice health gains to achieve it. The present review shows the many ways in which this concern manifests itself, and where further works needs to be done.

APPENDIX

The following three techniques are commonly used to measure the "utility" of different health states. Comparative studies reveal that they can produce quite different results (Torrance 1976a; Richardson 1994; Dolan, Gudex et al. 1996).

The Visual Analogue Scale (VAS)

With the Visual Analogue Scale (or rating scale) subjects are asked to indicate how much a health state does, or would, affect their quality of life by locating the health state on a line. The line usually has "full health" or "best imaginable health state" at one end, often indicated with a score of 100, and "death" or "worst imaginable health state" at the other end, often with a score of 0. (Note that "worst imaginable health state" allows for the possibility that some health states may be rated worse than death.) The health state being assessed may be the subject's own, in the case of a patient, or may be a defined health state, in the case of the general public. The VAS is assumed to be an interval scale. That is, moving someone from a health state with a rating of 70 to one with a rating of 90, is assumed to be twice as valuable as moving someone from a health state with a rating of 60 to one with a rating of 70. The validity of this assumption has been questioned (Nord 1999a, pp. 90-94).

The Standard Gamble (SG)

With the orthodox Standard Gamble (SG) the subject is offered two alternatives. Alternative 1 is a treatment with two possible outcomes. With probability p the patient is returned to normal health and lives for the remainder of his or her life; with probability $(1-p)$ the patient dies immediately. Alternative 2 is the certainty of living in the health state being evaluated for the remainder of the subject's life. Probability p is varied until the subject is indifferent between the two alternatives. The probability at this point is taken to represent the utility index. Some favour this techniques because it introduces an element of risk, which is a factor in most medical decision-making. On the other hand, the risk involved is part of the technique for measuring the "utility" of the health state, which is different from the risk involved in moving from one health state to another (Richardson 1994, p. 17).

The Time Trade-Off (TTO)

With the Time Trade-Off (TTO) the subject is offered two alternatives: alternative 1 (the health state, S, to be evaluated) for time t (often the life expectancy of an individual with the chronic condition) followed by death; and alternative 2, which is healthy life for a lesser period of time, $x,$ followed by death. Time x is varied until the subject is indifferent between the two alternatives at which point the utility value for state S is given by $U = x/t$. For some, this is the preferred technique as it most directly exposes the subject to the trade-off between life and quality of life (Mooney and Olsen 1991, p. 132; Richardson 1994, pp. 18-19).

Notice that the above three techniques measure the individual "utility" associated with a health state. They measure the value of a life saving intervention, or an improvement in quality of life, to the individual whose life is saved or improved. The *social benefits* arising from the intervention are ignored. The following technique is different in kind from the SG and TTO in this respect.

The Person Trade-Off (PTO)

With the PTO the subject is asked to compare two options each involving health improvement for a different number of people. The number of people in one option is varied until the two options are considered to be equally desirable. The value of the health improvements can then be inferred from the size of the two groups. For example, preventing the death (U = 0) of 10 people who will then remain in a poor health state A, may be valued as highly as saving the life of x people and restoring them to full health (U = 1). In this case the value of saving the life of someone who will remain in health state A, relative to the value of saving the life of someone and restoring him or her to full health, is x/10. In this case 10 (U(A) - 0) = $x \cdot$ (1-0) or U(A) = x/10. Nord, in particular, has argued for the use of this technique (Nord 1999a).

The VAS, SG and TTO encapsulate an individual's preferences about their own life. In the case of the RS: "How much does, or would, the following health state affect your own quality of life?" In the case of the SG: "How great a risk to your own life would you be prepared to accept for an improvement in health?" In the case of the TTO: "How much of your own life would you be prepared to sacrifice for an improvement in health?" By contrast, the PTO encapsulates an individual's views about the lives of others (possibly including themselves): "Which of these two groups should be the higher priority for treatment?" The PTO "asks subjects to make a social decision: to decide how to allocate resources between groups of people who have different health problems" (Prades and Lopez-Nicolás 1998, p. 287). Because it involves an impersonal trade-off

Table 26. Five Differences Between Utility Measures and Social Value Measures

(i) Utility elicitations require respondents to provide personal assessments of how they would feel about being in a certain condition.	**(i)** Social value elicitations ask respondents to focus on how the conditions would affect other people, or the society including themselves.
(ii) Utility elicitations ask people to think about (untreated) conditions.	**(ii)** Social value elicitations ask people to think about treatments, policies and programmes.
(iii) Utility elicitations do not require respondents to compare conditions with each other.	**(iii)** Social value elicitations require respondents to compare treatments (for different people), policies and programmes with each other.
(iv) Utility elicitations do not ask respondents to choose which people ought to get treated.	**(iv)** Social value elicitations ask respondents to choose which people ought to get treated.
(v) Utility elicitations do not allow subjects to make judgements of fairness.	**(v)** Social value elicitations allow subjects to make judgements of fairness.
(vi) Utility elicitations require respondents to adopt the perspective of a beneficiary, and to make assessment about their own well-being.	**(vi)** Social value elicitations allow subjects to adopt the perspective of an agent, and to give expression to their moral preferences and commitments.[a]

a   In elaborating his "capability approach" to evaluating social arrangements, Sen distinguishes between well-being objectives and achievements (which are self-interested), and agency objectives and achievements (which may include commitments that have nothing to do with a person's well-being): "In one perspective [the agency perspective], the person is seen as a doer and a judge, whereas in the other [the well-being aspect] the same person is seen as a beneficiary, whose interests and advantages have to be considered" (Sen 1985b, p. 208). Sen sees this distinction as "an essential and irreducible duality in the conception of a person in ethical calculation" (Sen 1987, p. 41).

between two groups the PTO allows the consideration of issues of justice and fairness. By contrast, when an individual is asked about the value of their own life, as with the VAS, SG and TTO, issues of fairness and justice do not arise. It is important to distinguish between these two perspectives because empirical studies show that individuals do not necessarily judge health improvements to

others as the same as health improvements to themselves (Richardson and Nord 1997; Dolan and Green 1998). Some of the differences between utility measures and social value measures, the first four of which are articulated by Ubel, Loewenstein et al. (Ubel, Loewenstein et al. 1996, p. 114), and the terminology used to describe these two perspectives, are given in Tables 26 and 27 respectively.

Table 27. Utility Vs Social Value: Instruments and Terminology

Study	Utility (SG[a], TTO[b], WTP[c])	Social Value (PTO[d], STTO[e], SWTP[f])
(Harsanyi 1955)	Subjective preferences	Ethical preferences
(Barry 1965)	Privately-oriented judgements	Publicly-oriented judgements
(Self 1975)	Individual preferences	Social preferences
(Dworkin 1977)	Personal preferences	External preferences
(Brandt 1979)	Self-interested desires	Non-self-interested desires
(Penz 1986)	Private wants	Social wants
(Nord 1999a)	Self-interest perspective	Caring-for-others perspective

a   SG = Standard Gamble
b   TTO = Time Trade-Off
c   WTP = Willingness to Pay
d   PTO = Person Trade-Off
e   STTO = Social Time Trade-Off
f   SWTP = Social Willingness to Pay

The PTO produces higher values for health states than the VAS, the SG or the TTO. In the case of two of these techniques, the VAS and the PTO, Ubel and colleagues attempted to determine exactly which differences are responsible for this discrepancy by controlling the differences (Ubel, Loewenstein et al. 1998). For example, they asked one group of subjects to rate a health condition on a VAS as if they had the condition themselves, a second group to rate it as if someone else had it, and a third group to rate the benefits of curing someone else of the health condition. Similarly, using the PTO, they asked one group of subjects to compare the relative benefits of curing two different conditions, and asked another group to choose which group of patients to treat in the context of budget constraints. (The first involves a comparison of benefit, the second a treatment choice.) They found that the discrepancy between the values derived from the VAS and the PTO cannot be explained by the fact that the VAS asks subjects to think about themselves, whereas the PTO asks them to think about others, nor by the fact that the VAS asks subjects to think about having conditions, whereas the PTO asks them to think about treating conditions. The authors suggest that it is the general format of the elicitation methods that produces the discrepancy (Ubel, Loewenstein et al. 1998, p. 43). By contrast, Nord suggests that the discrepancy may occur because VAS elicitations do not have explicit meanings for many people (Nord 1991). In brief, the reason for the discrepancy in scores is not fully understood, though the issue is of obvious importance for future work eliciting preferences.

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