

**Who Cares About Cost?
Does Economic Analysis Impose
Or Reflect Social Values**

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ACKNOWLEDGMENTS

The Health Economics Unit of the CHPE receives core funding from the Public Health Research and Development Committee of the National Health and Medical Research Council, Monash University, and the Victorian Health Promotion Foundation.

The Program Evaluation Unit of the CHPE receives core funding from the Victorian Health Promotion Foundation and The University of Melbourne.

The research described in this paper is made possible through the support of these bodies and by a project specific grant from the Public Health Research and Development Committee of the National Health and Medical Research Council of Australia.

ABSTRACT

In a two-stage survey, a cross section of Australians were questioned about the importance of costs in setting priorities in health care. Generally, respondents felt that it is unfair to discriminate against patients who happen to have a high cost illness and that costs should therefore not be a major factor in prioritising. The majority maintained this view even when confronted with its implications in terms of the total number of people who could be treated and their own chance of receiving treatment if they fall ill. Their position cannot be discarded as irrational, as it is consistent with a defensible view of utility. However 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.

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Introduction

Economic theory postulates that competing projects should receive a priority rating that is inversely proportional to their cost. In other words: If projects of type A are twice as costly as projects of type B, then society should choose As rather than Bs if and only if each A is considered more than twice as valuable as each B. This follows from the definition of cost, which is the value sacrificed by not putting resources to the best alternative use. Correspondingly, among equally valuable projects, the less expensive should have priority.

Less emphasis is often placed on costs in the health sector than economists would deem appropriate. The story of the Oregon experiment is interesting in this respect. It was a concern for the costs of Medicaid that led to the initial attempt to draw up a priority list based on the ranking of condition-treatment pairs according to their cost per Quality Adjusted Life Year (QALY). When the first list drew highly critical public reactions, it was concluded that too much emphasis had been placed on costs (Hadorn 1991). This inference was questioned by several writers, as the counterintuitive results could be linked to flaws in the benefit measure being used (Nord, Richardson & Macarounas-Kirchmann 1993). Nevertheless, the Health Services Commission in Oregon published a revised list of priorities a year later, based on a very different ranking procedure, in which costs played only a minor role.

Hadorn defended disregarding costs when determining priorities among health services by citing the 'Rule of Rescue', a principle initially formulated by Jonsen (1986). According to Hadorn, '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'. According to Jonsen, 'even the most evangelical utilitarian would find it difficult to expunge the rule of rescue from the psychological dynamics of technology assessors' (Jonsen 1986 p174). Hadorn adds that 'although the Rule of Rescue clearly is most compelling in the context of lifesaving interventions, it is also a factor whenever an identified patient is in need of treatment (eg for a fractured arm)'.

At a semantic level we might disagree with the implication that the Rule of Rescue conflicts with utilitarian principles. As argued by McGuire et al (1988), individuals might obtain 'process' or indirect utility from the way in which the health system is organised; from the knowledge that

health care is accessible and that the individual is living in a 'just' society.¹ Economic theory acknowledges the possible importance of such utility and explicitly allows for an equity/efficiency trade off (Culyer & Wagstaff 1990; Wagstaff 1991). Jonsen and Hadorn's criticism is of simple 'utilitarianism' in which only the direct utility of the outcome is recognised and in which costs must play a dominant role as they measure the value of foregone direct utilities. The substantive issue is that Jonsen and Hadorn describe an ethical system which significantly lessens the importance of costs. Such a system may have popular support.

The tendency for people to disregard costs in prioritising in health care has been observed in a recent Norwegian study. In a series of seminars attended by politicians, health administrators and health personnel, Nord (1994a) asked the participants first to rank a set of medical interventions according to their valuation of the outcomes. The participants were then informed of the cost of each of the interventions and were asked to rank them again, but this time according to the priority they thought the interventions should have within a given, limited budget. Although the costs ranged from Nkr 2,000 to 500,000, the rankings in the two experiments were remarkably similar. Very costly interventions ranked only slightly lower on the second priority list than on the initial valuation list. Inexpensive interventions tended not to improve their ranking at all. This result suggested that costs were not assigned much importance in the participants' decision making, and several of the participants confirmed this hypothesis when confronted with the similarity of the results of the two evaluations.

In the present study we report the results from a two-stage survey in which a cross section of Australians were questioned about the importance of costs in prioritising health care services. The results are consistent with the Rule of Rescue and lend support to the view that there may be significant indirect utility associated with the process by which medical services are provided. This calls into doubt the simple algorithms often suggested for achieving allocative efficiency on the basis of the 'direct' utility arising from medical outcomes.

Data and Methods

Stage 1

The first stage of the study was part of a general survey about prioritising in health care (Nord, Richardson, Street et al 1994). The survey used a self administered questionnaire with the following preface:

'In our society there is not enough money to give all patients all the health care they want. There is also a shortage of donor organs for patients in need of organ transplantations. In practice, this means that some patients get treated more quickly than others. It can also mean that some patients receive certain kinds of expensive treatment while others do not. In both cases we may say that some patients are given priority over others.

On what basis should priority be given? This is the question that we are asking you to consider in this study.'

Priorities can be set between diagnostic groups (eg hip replacements versus heart surgery) and within diagnostic groups (eg whom to select for hip replacements). The distributional rules that people want to apply at these two levels of resource allocation need not be the same. In *Stage 1*,

¹

McGuire et al. contrast 'process utility' with what they describe as 'consequentialist utilitarianism', ie the notion that it is the outcome or consequences of the states of the world that alone bear utility (p46). The terminology is, to us, confusing as the benefits associated with 'process utility' are also a consequence of the provision of particular services. To avoid semantic confusion we refer to 'direct utility' as the health or consumption benefits to individuals arising from their receipt of medical care and 'indirect utility' as the utility arising from the process.

the questions encouraged the subjects to think mainly about priority setting *within* diagnostic groups that is, the questionnaire sought to abstract from issues associated with the type of illness and focus attention upon individual characteristics. General results are reported elsewhere (Nord, Richardson, Street et al 1994).

One of the questions addressed the issue of the *direct costs* of treatment. Two different views were presented, one advocating priority for low cost patients and the other assigning priority regardless of cost except when costs are 'extremely high'. Another question addressed the issue of *indirect cost*. Again, two different views were presented, one giving higher priority to people on sick leave and the other assigning priority regardless of participation in the work force. On each issue, the subjects were asked to indicate the view that came closest to their own. They were also asked to indicate if they found the choice very difficult, slightly difficult or not difficult at all. They were encouraged to add comments. Information was also obtained about the personal characteristics of the respondents.

Stage 1 was designed to allow for the recruitment of subjects for subsequent, more detailed interviews in *Stage 2*. To facilitate data collection in this second stage, the majority of self administered questionnaires were distributed in the city of Melbourne, Australia, where the project was based. Five districts of Melbourne were selected, representing different levels of socioeconomic status. In addition, four towns across Australia were included in the data collection to test the representativeness of the main results. For each of the Melbourne districts, the method of distribution of the questionnaires was as follows: A map was obtained that showed socio-economic variation within the district according to 1986 census data. A route was arbitrarily drawn up that led through various sub-areas that together represented a broad range in terms of socio-economic status. Along this route, a copy of the questionnaire and a covering letter was dropped in every second mail box. In the four towns elsewhere in Australia, subjects were randomly selected from the telephone directory and sent the questionnaire by ordinary mail.

In a covering letter, each household was asked to select the person over 17 years whose birthday was closest to the first of January (or - in half the cases - the first of July). Respondents were offered a scratch lottery ticket as a reward. There were 551 useable responses, of which 440 were from Melbourne.

Stage 2

60% of those who responded to the self administered questionnaire said they were willing to participate in a follow up study. These included 260 subjects in Melbourne. Individual interviews were conducted which were primarily concerned with establishing the trade-offs people would make between different types of health care programs. However, additional questions were asked to validate and help interpret the results from *Stage 1*. To limit the length of these interviews, the 260 subjects were assigned to four different groups A-D, each of which was asked different sets of questions. Group assignment was done by first stratifying the subjects by sex, age and educational level and then randomly distributing each stratum across question sets.

Interviewing took place 2-3 months after completion of the self administered questionnaire. In 84 of the 260 cases, it was not possible to conduct an interview, mainly because the subjects had changed their mind or were very difficult to contact. The effective response rate from participants in *Stage 1* was therefore 41%. However, 57 interviews were conducted before deciding to include follow up questions about costs. Thus, a total of 119 interviews were completed which included questions about costs.

The cost question in the *Stage 1* self administered questionnaire was given to 45 people in group A to test the reliability of the initial responses. A slightly modified version of the question, which emphasised the budget limitation, was given to 38 people in group B. The *Stage 1* question relating to sick leave was presented a second time to 47 people in group C. With each of these three questions, subjects who chose *not* to discriminate on the basis of cost, were asked to explain their reasons. Finally in all 119 interviews, subjects were asked at the end of the interview to allocate a fixed budget between high cost and low cost patients in such a way that they were forced to recognise the smaller number of patients who would be treated as a result of their allocation of funds to high cost patients.

The exact formulation of questions and views are reported below together with the results.

Results

Descriptive Statistics

Descriptive statistics are presented in Table 1. Subjects who were interviewed about the cost questions were more likely to have private health insurance and were more likely to have received tertiary education and hospital treatment in the past two years than were those who returned the questionnaire but were not interviewed. Compared with the Australian population, there was a strong overrepresentation of people with tertiary education and a slight overrepresentation of women and non-smokers.

TABLE 1
Descriptive Data

	Definition	Questionnaire Respondents	Interview Subjects
Number		551	119
Gender	Percent female	57	60
Age	Mean (SD) years	46 (\pm 17)	47 (\pm 16)
Educational level	Percent with tertiary qualifications	49	63
Main occupation	Percent in the paid work	53	46
Language	Percent English speaking	87	92
Smoker	Percent	16	12
Health status			
	Hospitalised within past two years (%)	34	39
	Long term problem		
	• major (%)	8	6
	• slight (%)	24	28
Private insured	Percent	51	63

The importance of the over-representation of the privately insured and the highly educated populations were tested with *Stage 1* data using both CHI^2 and logit analysis. No significant association was observed between these two variables and any of the response variables. Similarly there was no statistically significant difference between responses in Melbourne and in the four towns. We have no reason, therefore, to doubt that the results are representative of the views of most Australians despite the low response rate (for details see Nord et al (in press)). The reliability of results was tested by commencing *Stage 2* interviews with two or three of the questions from the self administered questionnaire. In such re-tests 80% of the responses were the same as in *Stage 1*.

In the following we provide details about option formulations and comment on the results - first with respect to direct costs, then with respect to indirect costs. Differences between subgroups are mentioned only when they are significant at the 95% level or above. A general discussion follows in the final section.

Direct Costs

The self administered questionnaire of *Stage 1* presented the following options:

- 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 a high cost illness. Priority should therefore not depend on the cost of treatment (except in cases where costs are extremely high).*

In the preface to the questions subjects were asked to assume that the patients were the same except for the difference mentioned. Consequently, the first group would be selected if cost effectiveness was the sole criterion.

The results are shown in the first two lines of *Table 2*. Indirect costs are discussed later in the text. With respect to direct costs, 81% chose the second option, rejecting cost as an important criterion for assigning priority. Of these, 82% made this choice with only slight or no difficulty. A logistic regression using gender, age, education, smoking behaviour, insurance status, long term health status, recent hospitalisation, occupation and location as explanatory variables showed that women were 1.79 times more likely than men ($p=0.01$) and smokers 2.5 times more likely than non-smokers ($p=0.03$) to choose the non-discriminatory option.

TABLE 2
Percent Response to Each Issue and Difficulty of Choice

Issue	Option	Percent Choosing each Option	Difficulty of Choice		
			Very difficult (%)	Slightly difficult (%)	Not difficult (%)
Direct Costs	<i>Favour least costly</i>	18.6	39.6	29.2	31.3
	<i>Equal priority</i>	81.4	18.1	25.7	56.2
Indirect Costs	<i>Favour workers</i>	12.6	21.2	37.9	40.9
	<i>Equal priority</i>	87.4	7.2	13.2	79.6

Prima facie, the results represent a decisive rejection of the conventional economic framework for establishing priorities. However, it was hypothesised that the results may have been influenced by the questionnaire design, by framing effects and/or by the respondents poor appreciation of the implications of their choices. Respondents may have disregarded the instructions and assumed that high cost treatments produced greater benefits. The following procedures were carried out to test these hypotheses.

In *Stage 2*, 45 subjects in group A were presented with the same options but in the context of a personal interview. Reliability was moderate, with 78% selecting the same option in *Stage 1*. (Kappa = 0.31) 78% chose option 2 (equal priority) in *Stage 2*.

Thirty eight subjects in group B of *Stage 2* were presented with a modified version of the direct cost question, in which the preface drew greater attention to the budget limitation:

Consider a situation in which a given hospital budget is to be spent on treating different groups of patients. The groups are equally ill. But the cost of treatment varies between the groups. Which of the following comes closest to your view?

The options were the same as those presented to Group A, except that the words 'should have priority' in option 1 were replaced by the weaker expression 'should have *some* priority'. It was hypothesised that in the modified version option 1 would be a more obvious choice.

The result was that 30% chose to favour the low cost patients, as compared to 22 % with the original version. The difference is not statistically significant. A clear majority of 70% still preferred the equal priority option.

Those who chose the equal priority option in *Stage 2*, either in the simple retest or with the modified question, were challenged further about their position:

It seems inescapable that if money is limited, then it would be possible to help more people if some priority were given to those who are inexpensive to treat. Still you chose the second view. Can you explain a little further how you think about this?

In their answers, the respondents emphasised that people cannot be blamed for getting high cost illnesses, that severity of illness should count rather than cost, and that people were equally entitled to treatment irrespective of cost.

The respondents were then asked:

So this is your view even if fewer people would be treated and your own chances of benefiting would be smaller?

Nobody changed their mind, and several explicitly accepted the consequences in terms of a reduced chance for themselves to benefit personally.

In 119 interviews in *Stage 2*, the subjects were presented with a numerical example that made it very clear how different rules for prioritising between low cost and high cost patients would affect the numbers of patients treated as well as the chances of any one individual receiving treatment if he or she should fall ill. Subjects were told that the treatments were equally effective and then asked which prioritising rule they preferred in the light of these explicit implications, after having been presented with brief arguments in favour of each rule. *Frame 1* shows the first part of this exercise, where the choice was between Rule A where resources are allocated to the less expensive patients; and Rule B where spending is determined on a first come first serve basis.

Frame 1

E1. Imagine two illnesses X and Y. People get them through no fault of their own. The illnesses are equally serious and leave the patients in a state of *severe disability* if untreated. They both occur in about *100 people per year* in your country. You yourself are *equally likely* to get either of them.

A *basic care* is offered to everybody who gets either of the illnesses. Beyond this basic care, there are treatments available for both

illnesses that are *equally effective* and will improve the patients' functioning considerably. The treatment costs, however, depend on the illness:

Illness X: \$ 20,000 per patient
 Illness Y: \$ 100,000 per patient

Imagine that society decides to allocate 1 million dollars per year to these treatments. This is not enough to treat all patients, so a rule must be decided as to who should have priority. Two different rules are suggested.

Rule A would be to spend all the money on people with illness X. This would lead to the following numbers of people being treated per year.

X: 50
 Y: 0
 Sum: 50

Rule B would be 'first come, first serve'. On average, this will lead to the following numbers of people being treated per year.

X: 10
 Y: 8
 SUM: 18

Advocates of rule A argue that it would allow more people to be treated and thus all in all lead to less disability and suffering in the population. It would also give each of us a better chance of actually benefiting one day, since more people would be treated and the illnesses are equally common.

Advocates of rule B argue that it is unfair to discriminate against those who happen to get a high cost illness through no fault of their own. They argue that this concern for fairness should override the concern for treating as many as possible. The two groups should therefore be treated on a first come, first serve basis, even though fewer people would then be treated.

You are yourself a member of the society in which one of these rules would apply. Which of them would you vote for? Take a look a look at this summary and think carefully before you answer (rules and consequences were shown).

The interview results are summarised in Table 3 under the heading *Frame 1*. Rule B (first come, first serve) was preferred to Rule A (spend all money on low cost patients) by 82 (68%) of the 119 interviewees. A logistic regression was performed using the choice between Rule A and B as the dependent variable and gender, age, education, occupation, smoking behaviour, insurance status, long term health and recent hospitalisation as explanatory variables. No subgroup was observed to be significantly more likely to choose one rule over the other.

TABLE 3
 Choices Among Three Rules for Resource Allocation

<i>Frame 1</i>			<i>Frame 2</i>					
<i>A v B</i>	<i>Number</i>	<i>%</i>	<i>A v C</i>	<i>Number</i>	<i>%</i>	<i>B v C</i>	<i>Number</i>	<i>%</i>
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)

A third compromise Rule (C) was then presented to the same subjects, suggesting that priority should be given to low cost patients, but that some capacity should be allowed for the treatment of high cost patients, (see *Frame 2*). Interview results are shown in Table 3 under the heading *Frame 2*. Of the 37 interviewees who originally chose Rule A, 54% opted for Rule C (some priority to low cost patients) when this was offered in *Frame 2*. Similarly, 52% of those who initially chose Rule B over Rule A later selected Rule C when it was presented. Overall, Rule C was the preferred choice, being selected by 63 (53%) of the 119 subjects. 39 subjects (33%) preferred Rule B even to Rule C, i.e. they rejected giving priority on the basis of cost. Only 17 subjects (14%), preferred Rule A to both B and C. In other words, only a small minority would maximise the health benefits by spending all the money on the low cost patients.

Frame 2

E2. A third rule C is suggested. 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. They therefore suggest that priority should be given to patients with illness X, but some capacity should be allowed for the treatment of patients with illness Y.

Again, as a member of the society in which one of these rules would apply, which of C and (A or B) would you vote for?

Finally, those who preferred Rule C were shown five possible ways of dividing the budget between the high cost and the low cost group (the 'production frontier') and asked which of these outcomes they would select (*Frame 3*). Results are given in Table 4.

Frame 3



Of the 63 subjects who selected Rule C, 30 (48%) chose option III for dividing a given budget between two illnesses, as specified in *Frame 3*. This option entails that of the 50 patients who it would be possible to treat, 34 are actually treated. Of these, 30 (88%) patients with illness X receive treatment. 17 subjects (27%) chose option II in which a total of 26 patients receive treatment, 77% of these suffering from illness X. Four subjects chose the fifth combination, which was inconsistent with their expressed preference for Rule C. Of these, three subjects had originally expressed a preference for Rule A over Rule B. In sum, the results indicate that 94% of these patients preferred to allocate the budget in a way that did not maximise the number of patients who would be treated. Their preferences cannot be attributed to poor information or a misunderstanding of the consequences of their decision as the framing of the question forced a recognition of the true opportunity cost.

TABLE 4
Allocation of \$1m to Two Illnesses

<i>Frame 3</i>		Numbers treated under each Option									
		I		II		III		IV		V	
<i>Illness</i>											
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)

Indirect Costs

The self administered questionnaire of *Stage 1* presented the following options:

- 1 *Working people and non-working people should have equal priority when they have the same illness.*
- 2 *To limit possible economic losses to the country, people in the work force should have some priority over non-working people on hospital waiting lists.*

The results are shown in Table 2 above. 87% chose the former, non-discriminatory option, rejecting workforce participation as an important criterion for assigning priority. Of these, 93% made this choice with only slight or no difficulty.

In *Stage 2*, 47 subjects in group C were presented with the same options in an interview context. Reliability was high, with 93 % choosing the same option as they had done in *Stage 1*. (Kappa = 0.56) 98 % chose option 1 (equal priority) in *Stage 2*.

A logistic regression using the explanatory variables previously mentioned showed that women were more likely than men to choose the first option (odds ratio 2.11, $p=0.009$). No other significant results were found.

Those who chose the equal priority option in *Stage 2* were asked the following:

It seems inescapable that some production losses could be avoided if people on sick leave were given some priority so that they could return to work more quickly. Still you chose the second view. Can you explain a little further how you think about this?

Some respondents did not accept the premise that there would be production losses related to sick leave. However, the majority answered that people were not to blame for loss of employment, that everybody contributes to society and that there should be equal entitlement to treatment irrespective of employment.

The respondents were probed further with the following question:

What if we are talking about people who are not easy to replace, for instance managers or people with special professional skills? Would you accept giving some priority to these if they could thereby return to work more quickly?

Only a minority would accept giving priority to people with special skills. Those who would not accept this questioned the assumption that such people could not be replaced temporarily and also said that in general such people could afford to purchase private insurance.

Discussion

The respondents persistently rejected the idea of assigning priority to patients in inverse proportion to the direct cost of their treatment (with all else assumed equal). The majority would have assigned *some* priority to low cost patients, but they were willing to make sacrifices - both in terms of numbers of people treated and in terms of the chances of any one individual receiving treatment if he or she should fall ill - to ensure some degree of equity between high cost and low cost patients. Respondents also rejected the idea of giving priority in cases where non-treatment has a high indirect cost in terms of lost production.

Before drawing conclusions about the potential implications of these findings for cost-effectiveness analysis, their reliability and validity need to be established.

The study first used a self administered questionnaire where respondents were asked to choose between conflicting views. The results in Table 2 do not suggest that respondents generally found decision making to be very difficult. This is also supported by the good concordance between test and re-test results at the individual level. In addition, those who preferred the equal priority options held firmly on to their views when probed and were generally able to support them with coherent arguments. Overall, we feel confident that the responses to the self administered questions are reliable.

The respondents in the study were a self selected group, with a strong overrepresentation of people with tertiary education. For this reason, and because of the low response rate, we cannot draw strong conclusions about the whole Australian population. However, there are good reasons for believing that the results may be generally true. The logistic regressions indicated little variation in the pattern of response by age, socio-economic status or previous health history. Even when statistically significant differences occurred in the percentage of respondents selecting an option (notably the more pronounced rejection of costs as relevant for prioritising by women and smokers), the differences were not of such a magnitude to suggest that a different group of respondents would have altered the main conclusions.

In all surveys respondents are sensitive to the framing of questions. This was particularly true in the present study where questions were not straightforward: rather, subjects were asked to select between alternative points of view in the light of summarised but persuasive arguments. While the possibility of framing effects cannot be eliminated (questions and arguments must be framed!), considerable effort was exerted to ensure the neutrality of expression and presentation. It is also hard to see that the implications of different choices could be made more clearly than in the numerical examples used in this study. With sufficiently persuasive arguments it may have been possible to alter the subjects' responses. However, the objective of the survey was to elicit present views and not to reshape them.

In sum, we find little reason to doubt that the preferences for equity that we have observed in our study are firmly held by well informed subjects. We also suspect (but cannot prove) that our results are quite representative of attitudes in the general population in Australia. As noted in the introduction, similar attitudes have previously been observed in other countries. The important question to address is whether they are simply the result of short-sightedness with respect to either the economic and/or the moral consequences of the choice, or, alternatively, whether the attitudes have a substantive, and defensible basis that economists need to incorporate in their methods for priority setting in health care.

One possible objection to the results from *Stage 2* in our study is that, even if the implications of Rules A, B and C were made very clear, the respondents may not have taken full account of them. It is well known that people adopt simplifying procedures (heuristics) in complex decision making (Schoemaker 1982). For example, in the summarised case for rule B (see Frame 1) it is argued that this rule achieves 'fairness'. A simple heuristic device might be to adopt the apparently fairest rule, ie B. It is possible that with greater reflection the respondents might have concluded that, from behind a Rawlsian veil of ignorance there would be no inequity in favouring low cost patients as everyone is equally likely to get either illness and the choice of the low cost alternative would only increase everyone's chance of benefiting. Even when this latter argument

was put explicitly to the respondents (see *Frame 1*, third last para), it is difficult to judge the extent to which it was understood and actually taken into consideration.

We cannot prove this possible objection to be false. However, all four interviewers reported that the subjects did not seem to have particular difficulty in understanding the arguments presented with our questions and there was no difference in the results between the better and less well educated. Respondents were also encouraged to take their time in answering and to consider the questions carefully. If, in spite of this, we obtained superficial views, then the process of eliciting reflective views is likely to prove to be very difficult.

Another possible objection is that the subjects may not have accepted the premise that there is not enough money to treat everybody. While comments made by some respondents suggested this, in the final question reported above the majority were prepared to allocate a fixed budget in such a way that health benefits were not maximised. This question was designed to prevent respondents avoiding the implications of a finite budget.

There would be less reason to doubt the reflectiveness and the validity of the respondent's views if they could be shown to have a potentially rational basis ie they were consistent with a defensible ethical position. We can envisage such a rational basis, as the result of three possible sources of indirect utility, that is utility which arises from the *process* by which health care is delivered as distinct from the health related *outcome*. As such, it is difficult to classify these sources of utility under the usual headings of an external demand or a meritorious commodity. Rather they represent a repudiation of the simple utilitarianism in which only direct utility is recognised.

First, despite the objective fact that more people may be treated and more health obtained by cost based discrimination, respondents might consider the *possibility* of treatment in serious health states to be of importance. This is consistent with the preference by many respondents for *Rule C* which explicitly included this argument (see *Frame 2*). In effect, a limited number of treatments offered to patients in a health state creates a rational basis for hope: no matter what health related event occurs respondents know there is a chance of treatment and hope is a rational basis for utility.

A possible objection to this argument is that the probability of treatment is greater with cost based discrimination when this probability is calculated from behind a Rawlsian veil of ignorance. However, as noted above, this information did not alter people's responses decisively. It is possible that respondents do not adopt a Rawlsian perspective: rightly or wrongly views on access may be based upon realised not anticipated illnesses.

A second source of (dis)utility may arise if respondents anticipate their own emotional response if they were seriously ill and were refused treatment despite resources being available, albeit at a high cost. While some patients might be phlegmatic and say to themselves: 'fair enough, I accept that I am the unlucky one who does not qualify for treatment because I happen to be costly to treat', many might not react in such a disciplined manner. Analogously, people *might* accept an explicit explanation from their family doctor that he or she would not be offered treatment because the societal cost of the treatment was too great. However, we would expect that most people would feel frustrated and resentful in such situations. Our data may indicate that a majority of Australians have a similar feeling in a less personal decision making context, namely that of deciding admission policies across diagnostic groups. The anticipation of such feelings might rationally lead respondents to pre-commit the system to the treatment of cases where non-treatment might lead to feelings of resentment or even outrage.

A third and closely related source of utility is the Rule of Rescue, described by Jonsen (1986) and Hadorn (1991). This is the sense of immediate duty that people feel towards those who present themselves to a health service with a serious condition. This sense of duty may lead people to feel that the society is callous or uncaring if it withholds expensive treatments when resources are available at the moment of demand. To follow this sense of duty may lead to queuing and fewer people being treated, but these consequences may not be considered as undesirable as withholding possible treatment from those in great need. Such subjective feelings are a legitimate basis for utility.

As noted by Hadorn society cannot possibly yield to the Rule of Rescue in every case of apparent need as this would lead to an extremely expensive health care system. But Hadorn argues that the cost effectiveness approach of traditional health economics should be replaced by the approach adopted in Oregon in 1991 to produce a revised priority list. In this approach services were assigned priority mainly on the basis of net expected health benefit. According to Hadorn this approach provides 'a reasonable compromise between a public good, direct utilitarian framework and the need to accommodate the rule of rescue'. While we do not necessarily endorse Hadorn's conclusions, they illustrate the changes to the basis of the economists approach to resource allocation that could follow from an acceptance of a fully inclusive utilitarian approach which recognised the existence of indirect utility, as well as the direct outcome related sources of utility presently incorporated in cost-effectiveness analysis.

Conclusions

From the above discussion we draw the following conclusions:

- 1 Many people in Australia take the view that the cost of treatment should not count heavily in determining priorities between different diagnostic groups when withholding treatment leaves patients in a state of severe disability. This view is held by such a large percentage of our respondents and varies so little between groups that we believe that it is probably an accurate reflection of the views of the general population.
- 2 Subjects uphold this view even when its potential implications are clearly demonstrated in terms of fewer patients being treated and the smaller chance of any one individual receiving treatment should he/she fall ill.
- 3 The view is not necessarily due to a lack of reflection. It may be linked to psychological mechanisms that operate in the presence of serious illness, and which we have argued are forms of indirect utility, that is, utility arising from the process of service delivery.

As a minimum, these conclusions suggest a general willingness to make quite significant sacrifices in terms of 'efficiency' - health maximisation - to achieve goals of equity or social justice. This, in turn, suggests that algorithms for the maximisation of 'social utility' such as the QALY league table should be treated with considerable caution. While they may indicate how to obtain the greatest health benefits they disregard process considerations that the population may feel to be of great importance in the treatment of severe illnesses.

It is possible to avoid stronger policy conclusions by arguing that, despite our attempts to clarify the implications of ignoring costs, our respondents have not presented us with a reflective view; i.e. that they have not recognised the full consequences of their choices. However, the aim of

the survey was to elicit current views and not to change these through debate. It is, of course, possible that respondents did not understand the consequences of these choices despite our attempts to present them clearly and explicitly. We feel, however, that some burden of proof lies on those who prefer this interpretation.

It is also possible to minimise the policy implication of these views by using ethical rather than empirically based arguments to maintain that such views *should not* be taken into account in decision making; that direct utilitarianism that disregards sources of indirect utility is a superior basis for the allocation of resources. The implication of this position is that economic evaluation is not simply maximising societal welfare, as this is usually defined in terms of society's own values. Rather, it is imposing, a set of values believed to be more rational or better justified than those held by most members of society. Those who take this approach must then face the task of showing that the values they defend really are more rational or better justified than the more widely held values they wish to override.

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