

HOW SHOULD WHAT ECONOMISTS CALL 'SOCIAL VALUES' BE MEASURED?

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Abstract: Most economists and some philosophers distinguish individual utilities from interpersonal social values. Even if challenges to that conceptual distinction can be met, further philosophically interesting questions arise. I pursue three in this paper, using, as context for the discussion, health economics and its attempt to discern empirically a social welfare function to help guide rationing decisions. (1) *To discern these utilities and values in a manner that is morally appropriate if they are to influence rationing decisions, who should be queried?* To discern individual health state utilities, persons in precisely those states should be asked (generically, 'patients'), but for social values, representatives of the general public should be. (2) *To discern social values, what should representatives of the public be asked?* They should be asked 'person trade-off' (PTO) questions that encompass their own self-interest, not PTO questions that focus only on others. (3) *What must public representatives understand before they respond to such questions?* Despite the philosophically complex problem of patient adaptation, they should understand (among other things) the health state utilities elicited from actual patients with the conditions at issue.

Key words: philosophy of economics, individual utility, social value, health economics, cost-effectiveness analysis, Person Trade-Off method, adaptation

I. The Distinction Between Individual Utility and Social Value

In classical welfare economics, a distinction is drawn between *individual utilities* and *social values*. Individual utilities convey information about the welfare of an individual. They focus on the well-being of the individual whose utility they are, not on the well-being of any community of persons or directly relational values between persons. Such utilities may be discerned by observing the behavior of the persons whose utilities they are, by tracking the responses of those persons to questions about their own individual well-being, or by a variety

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of other methods that focus on what people value in their own lives. By contrast, social values constitute preferences or evaluative claims about an aggregate or community of persons. The social (societal) values that people believe apply to a given community may or may not be a direct function of the individual utilities of the community's members.¹ What economists call welfarist utilitarianism is the view that a community's social welfare function is simply the sum of the individual utilities of all the community's members. In that view, societal value is maximized by maximizing the sum of all the individual utilities of a community's members. Welfarist utilitarianism, of course, is only one particular view of societal value in a community of persons; there are other, non-utilitarian views of a community's social welfare function as well.

One way to approach the question of whether a particular community's social welfare function is utilitarian or not is to discern whether or not its *individual* members' views of societal value line up with this welfarist utilitarian view. That can be discovered by eliciting and studying people's responses to various propositions about what would be better for their society. Insofar as their responses matched, or differed, from a utilitarian social welfare function, we might say that the community's social welfare function was or was not utilitarian. While speaking of *individuals'* social welfare functions—in contrast to the social welfare function of a community—may not be a paradigmatic way of speaking, it is one conceptually coherent way to parse the distinction between individual utility and societal value. We could then speak of three distinct elements of value. (1) Various individual utilities would characterize the welfare of society's members. (2) Most individuals would also have preferences about what constitutes *their society's* well-being, something that would often include relational or distributive values. These would be societal values as expressed by individual members of the society—"individual social welfare functions," we might say. (3) The *society* may also be said to have its social welfare function, which may or may not be generated by individual members' societal values.

The distinction between individual utility and either of the two senses of societal value can be illustrated by the interesting questions provoked when people have to allocate resources between various curative and lifesaving health care services. Take two non-life-threatening conditions such as meningioma and chronic knee impairment:²

Meningioma is an abnormal growth in the tissue lining of the brain that causes relatively constant headaches that are often severe. While the pain can be decreased

with common medications, it cannot be *greatly* reduced, much less eliminated, without interfering with ability to concentrate. Those common medications are, though, generally necessary to allow sleep. This painful, abnormal tissue growth is not cancerous, nor does it itself effect longevity.

Chronic knee impairment is a deterioration of the inner knee cap surface and surrounding tendons that prevents athletic activity and frequently causes the knee to give out in walking. In addition, one's knees genuinely ache for roughly an average of an hour a day, to the point that it is very difficult to concentrate. The rest of the time, normal life functions are not disrupted.

Now imagine that we add to the mix of these two conditions in a given population the presence of appendicitis, which is distinctly life threatening but for which there is virtually always a successful, though hardly inexpensive, treatment (appendectomy). Moreover, suppose that two new, expensive, and highly successful treatments are developed—full cure for meningioma and surgical knee reconstruction. Moreover, there are insufficient funds to provide all the useful meningioma cures, knee reconstructions, and appendectomies that patients want and physicians are medically prepared to prescribe. That is, these three services (among others) need to be prioritized. Which treatment, at the margin, produces the most individual utility, and which produces the most societal value? How would we go about discerning either of those?

Let me describe the established method for addressing these questions that has been developed in health economics, a method which I will then argue ought to be significantly revised to include societal values.

II. Conventional Cost-Effectiveness Analysis and Its Deficiencies³

Cost-effectiveness analysis in health care (CEA) is designed to tell policy makers how much health-related value different resource investments are likely to produce. It does much more than compute the net monetary costs of interventions. It expresses the “effectiveness” side of its work in common units of health-related value such as Quality Adjusted Life Years (QALYs) that combine life itself and quality of life into a single metric.⁴ When the conventional

methodology of measuring QALYs is probed, we find out that they are units of individual health-related utility. Technically, then, what passes for generic CEA is usually more specific—namely, cost-utility analysis (CUA).

Theoretically, the work that CUA and CEA can do is indeed remarkable. They can take programs with qualitatively very different outcomes—lifesaving dialysis or appendectomies and quality-enhancing hip replacements, meningioma cures, or knee reconstructions, for example—and inform us of their costs in relation to their respective *comparable* effects (their QALYs, e.g.). How is the single metric of value for comparing widely different effects obtained? Typically this metric incorporates three factors. The first, and by far the most complex conceptually, is *the size of the improvement in health-related quality of life* (HRQoL) produced by treatment: the saving of life and its maintenance at a certain subsequent level of HRQoL, or the raising of a lower level HRQoL to a higher one. It is here, in the evaluated “size of treatment effect,” that mortality and morbidity are combined. Death is assigned the value 0, full health the value 1.0, and all other health states better than death are arrayed in between, from most to least severe. These other health states—the various degrees and types of morbidity—are given specific numerical values between 0 and 1.0 on the basis of responses that interview subjects give to certain questions.

Various types quality-of-life eliciting questions are used by different practitioners of CEA.⁵ Take one of the common ones, “time trade-off” (TTO). Respondents—whether they be people with or without experience of such a condition—are asked how many of an anticipated 10 remaining years of their lives with kidney dialysis, say, they would be willing to sacrifice in order to obtain a complete cure of their condition. Suppose that on average their answer is 2—that is, 20 percent of the remaining time they would otherwise live. Then they have rated the quality of life with dialysis at 0.8, a 20 percent reduction from 1.0. Others typical questions used are Standard Gamble (SG: if you had condition X, what risk of death would you accept in order to achieve a complete cure?), and Visual Analog Scale (VAS: if the bottom of this bar at 0 represents death and the top at 100 represented full health, where would you place your life were you in condition X?). TTO, SG, and VAS are all designed to measure individual health-related utility.⁶ Note that the questions they use all focus exclusively on the effect of the respondent’s real or imagined health state on his or her own self-perceived quality of life.

The second factor used to construct comparable units of value is the *duration* of that health improvement, and the third factor is the *number of persons* receiving it. Standard CUA incorporates and combines these factors in a simple mathematical way to yield an aggregate of units such as QALYs: the change in HRQoL (size of treatment effect) is multiplied by both the duration of that benefit and the number of persons so benefited. These factors are summarized in the following formula:

$$\# \text{ of QALYs} = \text{Change in HRQoL} \times \text{Duration} \times \# \text{ of Persons Affected}$$

Using all three factors, a lifesaving procedure like kidney dialysis and a quality-of-life enhancing treatment like hip replacements, for example, can be compared in their benefits, and thus in their cost/benefit ratios:

$$\text{HRQoL of kidney failure patient on dialysis} = 0.8$$

$$\text{Saving 1 patient with dialysis for 1 year generates } 0.8 \text{ QALY}$$

$$\text{HRQoL of life with severely impaired hip} = 0.79$$

$$\text{HRQoL of life after hip replacement} = 0.99 \text{ for 10 years}$$

$$\text{Providing 1 hip replacement generates } (.99 - .79) \times 10 \text{ yr} = 2.0 \text{ QALYs}$$

$$\text{Cost, hip replacement: } \$20,000 \text{ for 2.0 QALYs benefit} = \$10,000/\text{QALY}$$

$$\text{Cost, dialysis: } \$20,000/\text{year for 0.8 QALY} = \$25,000/\text{QALY}$$

The quantified effects of different services and programs that are derived in CEA are classic expressions of “utility” in a specific context—what health economists call “health related utility.” The CUA enterprise informs decision makers of which categories of health care investments will maximize the QALYs, or health related utilities, produced. Utilitarianism is obviously this method’s philosophical parent.

Note, however, that we could ask—and some health economists do ask—a very different kind of question to measure the value of health states and health care interventions: the “person trade-off” (PTO). Take, for example, Program A, which is stipulated to save 10 lives, and Program B that cures completely a chronic impairment for people at the same stage of life (age) as those saved by A. The PTO asks a respondent: How many people would Program B have to cure before you would believe it to be as valuable as Program A? If, for example, the response

was “50,” then the value of curing each one of the recipients of B is one-fifth the value of each of the lifesavings in Program A.

Note that the PTO does not focus on the value to herself of a person’s life in a given condition. The PTO pushes CEA out of its CUA mold and into the measurement of societal value.⁷ The focus in societal value, paradigmatically represented in what is elicited by PTO questions, is explicitly on *interpersonal* trade-offs—decisions about what services to provide among the wide array of possible services that often affect *different groups of people*. It is typically such interpersonal trade-offs that are at issue in the large-scale use of CEA for allocating preventive or acute care services at the “budget” or “coverage” level for large populations.

One of the clearest empirical studies that compares individual utilities with the societal values that people express focuses on cure of non-fatal meningioma, reconstructive surgery for chronic knee impairment, and lifesaving appendectomy. The relative priorities that would be predicted by CUA using a individual utility instrument like SG or TTO turn out to be very far from the priority relationships that people express in response to societal value questions in the form of PTO:

Table 1
**Number of Persons Cured of Meningioma or Knee Impairment
 Considered Equivalent to One Life Saved by Appendectomy⁸**

	<u>Implied by Utility Ratings</u>		<u>Directly Stated In PTO</u>	<u>Utility/PTO Discrepancy Factor</u>
	<u>With SG</u>	<u>With TTO</u>		
Meningioma	4 (.75 HRQoL)	10 (.90 HRQoL)	>800	> 80
Chronic knee Impairment	6 (.83 HRQoL)	17 (.94 HRQoL)	> 10,000	> 600

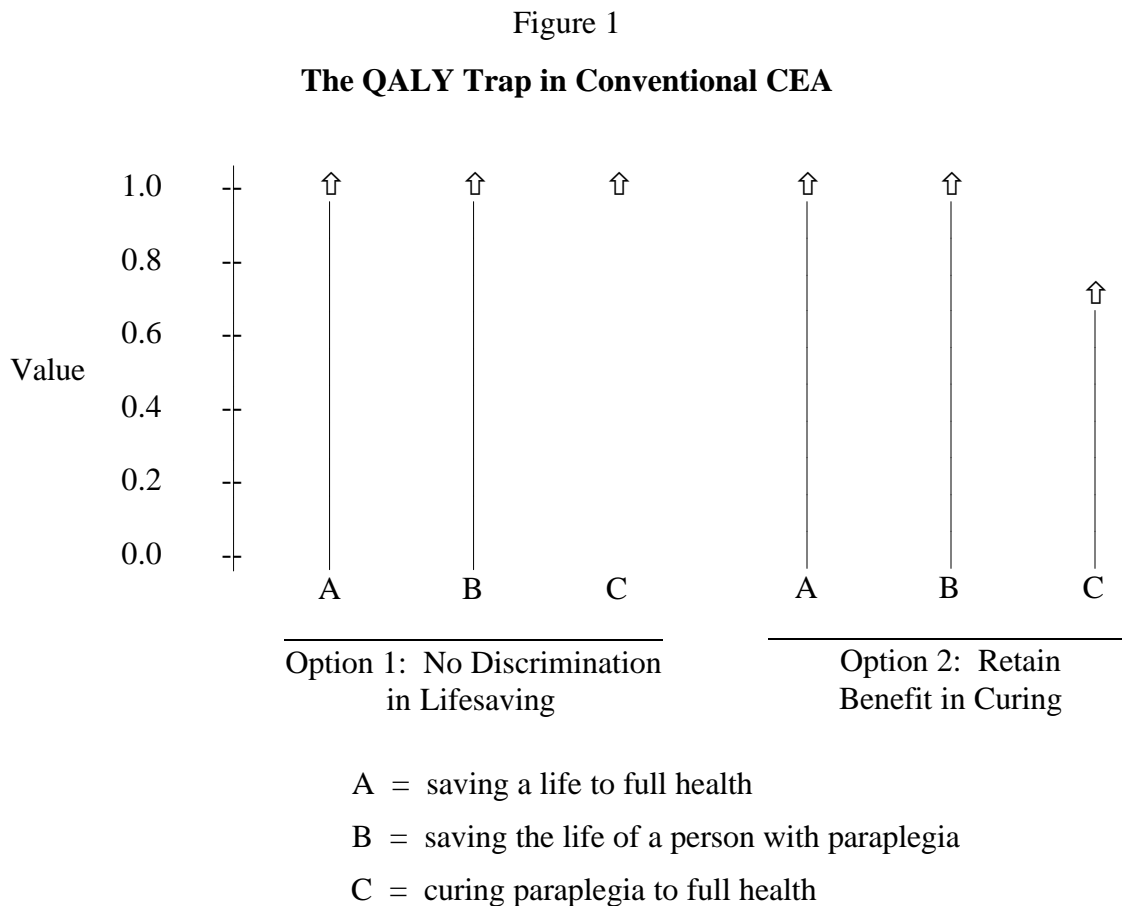
One way of summarizing such findings is to say that consideration for the special value of treatment in the face of death is not picked up by individual utility focused questions, even those like Standard Gamble that explicitly bring loss of life into their scope. When investigators shift respondents' attention from questions strictly about their own lives, such as TTO and SG, to questions of more societal scope such as PTO, the responses change markedly. What people are willing to do by way of their own risk gambles or time trade-offs is not the same as what they want their society to do when it comes to prioritizing health care.⁹ That is, what we might call people's "health-related social welfare function" is seldom utilitarian.¹⁰ Even when they understand what is at stake, they do not simply compare aggregate sums of individual health-related utility in making recommendations about health service trade-offs.

Empirical data about a different sort of example than the one about meningioma, chronic knee impairment, and appendicitis, which compared quality-of-life enhancement with lifesaving, might more clearly illustrate the conceptual coherence of societal value preferences that differ from individual utility preferences. This other sort of example would compare various treatments, *all of which save lives*, but which vary in *the different respective qualities of life* to which they save people.

PTO studies about this latter sort of case essentially show that except for life of extremely low quality, all lifesavings are thought to have virtually the same societal value. Imagine two groups of patients stricken with a life threatening illness. The first group were previously in full health and can be returned to full health with treatment. The second group previously had paraplegia and, with treatment of their life threatening condition, will continue to have it. Both, if treated, will live the same number of additional years. Assume that the HRQoL of paraplegia is 0.8, as calculated from TTO responses in which people, many actually with paraplegia themselves, expressed a willingness to sacrifice 20 percent of their remaining life extension to obtain a complete cure of paraplegia. Conventional CUA would then recommend saving the first group to full health before saving an equal number in the second group, and shifting priority to the paraplegia group only if the number of paraplegiac lives saved was at least 25 percent greater than the number of persons saved to normal health. Yet most of us, reflecting seriously about the value of continuing to live, believe it is no less important at all for society to save the lives of persons with paraplegia than the lives of others to full health.¹¹

Are such beliefs inconsistent with the prevalence of TTO responses that place the quality of life with paraplegia, say, at 0.8? We can see that they are not, once we recognize the distinction between judgments of individual utility and those of societal value. A disabled person’s willingness to accept a 20 percent shorter remaining life in order to be cured from a permanent disability (generating the 0.8 HRQoL) does not in any way indicate that she thinks that *her life, in relation to the prospect of death, is any less valuable and important to save than another fully healthy person’s life.*¹² The TTO preference is a judgment about individual utility, while a belief about interpersonal comparative lifesaving is a judgment about societal value. The 0.8 rating of health utility that expresses willingness to trade time within a life does not constitute a comparative judgment about the value of saving different persons’ lives, even to different levels of health-related quality. It is thus simply not, per se, a judgment about societal value.

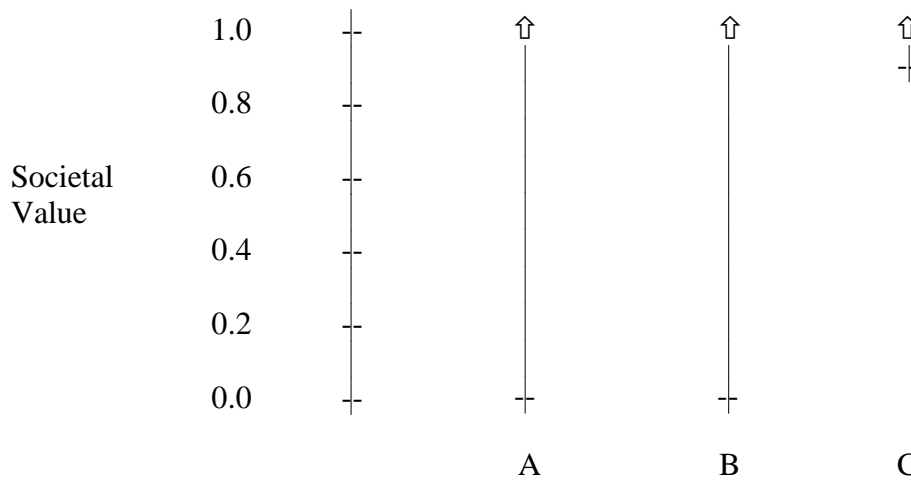
One way to grasp this is to speak of the contradiction between conventional CEA and our convictions about relative equity of lifesaving as the “QALY Trap.”¹³ It is illustrated by the following figure:



Within the conceptual confines of conventional CEA in which only health related utilities are measured and compared, one must choose between two options, both of which are objectionable. Either we regard saving lives to full health and to a life with paraplegia as equal in value but regard a cure for paraplegia as having no value, or we regard saving those two kinds of lives as unequal in value, with the difference in their value remaining as the value of a cure for paraplegia. The only way to escape this trap of two utterly objectionable options is to abandon the axiom that the value of saving a life to a condition of compromised health plus the value of curing that condition must be equal to—and cannot be more than—the value of saving a life to full health, as illustrated in Figure 2.

Figure 2

Escaping the QALY Trap: Abandon Assumption that $B + C = A$



- A = saving a life to full health
- B = saving the life of a person with paraplegia
- C = curing paraplegia to full health

Abandoning the assumption that $B + C = A$ poses little problem in a framework of societal values as distinct from health related individual utilities. The empirical values that are elicited by PTO questions, in fact, clearly reveal that people abandon this assumption.

My conclusion for this section of the paper is that CEA needs to incorporate a broader set of values—social or societal values—than the individual utilities incorporated by the conventional, welfarist, utilitarian form of CEA. This is not to say that empirical data about citizens’ societal value preferences should become the new mantra of health policy analysis. Cogent objections may be made to a practice of looking toward empirical PTO data to discern societal values. Norman Daniels, for example, objects to societal values discerned by empirical preference studies as a primary guide when distributive matters with such high stakes are at issue. He argues instead for openly deliberative, “political” procedures to discern or generate those values.¹⁴ A related view, but one more supportive of CEA, is the recommendation to incorporate “discourse ethics” into the process of eliciting preferences made by Andrew Edgar, et al., in their European Commission funded study, *The Ethical QALY...*¹⁵ It is not at all my intention to argue that in making rationing and prioritizing decisions in health care, we should simply use empirical data on societal values uncritically without public deliberation. It is only my intention to argue that if empirical preference data are going to be used in prioritizing health services, the inclusion of empirical studies about societal values will yield a more relevant set of data for health policy formation than the individual utility data that are almost exclusively used in the current practice of CEA.

III. Who Should Be Consulted to Discern Societal Values About Health Care Priorities?¹⁶

The question of whose values should be elicited to create comparative ratings—patients and ex-patients who have had the conditions being rated, or the general public—has been a major issue in CEA for some time. In measuring the size of an improvement in HRQoL, conventional CEA attempts to discern, not any objective health increment, but the subjective value or utility of the gain. Often, though, CEA has then proceeded to measure that subjective value in ways that do not include people who have had the health conditions being rated. This, of course, raises ethical doubts about sufficient inclusion in CEA of the perspective of those persons who will be primarily affected by the prioritizing policies that it influences.

Recently a consensus panel convened by the United States Public Health Service argued that *public* estimates of the utility of health gains ought to be used as the basis of cost-effectiveness measurements.¹⁷ Several arguments are typically cited for measuring utility from members of the general public rather than patients. First, CEA is a tool for determining how to allocate scarce societal resources. Consequently, it is society at large that should determine the values used in CEA, not patients with their own specific interests. Second, patients may overstate their health related quality of life either because of cognitive dissonance (it is difficult for them to admit how poor their quality of life is) or because of psychological adaptation (they lower their expectations so that their decreased function no longer bothers them). Third, proponents of eliciting utility measures from the general public argue that people can best evaluate the value of particular health states only when they are behind at least a partial veil of ignorance, where they are blind to their own self interest and to whether they will develop the health states in question. Thus, values should be elicited from members of the general public who have been asked to imagine that they could become stricken with the disease or illness in question, not from patients whose own self interests will contaminate their judgments.

On the other hand, several strong arguments favor eliciting patients' values for CEA. First, the general public does not necessarily know what it is like to experience the specific illnesses being evaluated in CEAs, whereas patients actually experience the illnesses in question. Short of the incompetence or incapacity of certain categories of patients, what would justify *generally* asking *other* people to judge the value of a health gain that is occurring primarily—even overwhelmingly—in the lives of patients? One can provide others with a rich description of the particular health condition they are asked to rate, but even then, why would one generally regard them as better judges of the value of life in that condition than those who have actually lived with it? Second, when conducting utility elicitation from the general public, we must describe the health states in question to the public. These descriptions will always be incomplete and, therefore, may introduce bias. Third, the public may be biased against people with disability or illness, stereotyping them as having a worse life than they do, and this may be reflected in value measurements.

Including societal values along with individual health utilities in the fuller enterprise of CEA presents the opportunity for a much more sophisticated resolution of this whom-to-ask

issue. The choice of whose values to solicit may not need to be either exclusively patients or exclusively non-patients. If individual utility and social value are carefully distinguished, then both patients and representatives of the general public can be included at their respective appropriate points.

Several economist colleagues and I have proposed that a two-stage process be used.¹⁸ Stage 1 would involve measuring the health related utility of patients with specific health states. Stage 2, via PTO questions, would involve discerning the relationship between societal values about interpersonal distribution, on the one hand, and increases in health related utility on the other. Respondents in stage 2 would need to know the nature of the conditions they were assessing, and part of that knowledge would involve understanding how actual people with those conditions rated their HRQoL.

In stage 1 the health related utility of specific conditions would be measured from patients who have the conditions being evaluated—individual utility, after all, is just the subjective value of a condition to the person who has it. In stage 2, however, where societal value is the focus, the argument for soliciting responses from the general public is much stronger. First, for the interpersonal judgments elicited by PTO questions, every person seems potentially qualified to express a preference. Thus wide representation of society would seem appropriate. Second, to elicit input only from those with the conditions in question may be limiting valuational data to a conflicted source. Representatives of the general public, blind to their own self interest because they do not know whether they will develop the health states in question, speak from behind a relative veil of ignorance. Patients' own self interests are more likely to affect their judgments questionably in these comparative matters of interpersonal trade-offs than in assessments of their individual utility.

A decision to elicit individual health-related *utility* data from patients rather than representatives of the general public would not be insignificant. Commonly, ratings by patients of their own HRQoL—especially those by chronically ill patients—are higher than ratings of the same health states by those who have not directly experienced them.¹⁹ Admittedly, the empirical evidence is somewhat mixed. Some studies show little systematic difference in patients' as opposed to non-patients' perceptions of the HRQoL for a given condition, and these could be taken as countering the studies that reveal higher ratings by patients. Notably, though, no studies

reveal patient ratings that are *lower* than those expressed by non-patients. Thus the balance of current evidence still distinctly points toward a difference.

As a matter of fact, then, the elicitation of health state utilities from actual patients will make a difference. But once that is done and the resulting information is used to describe how people react to particular conditions, representatives of the general public stand in a much stronger position to register their societal value preferences about trade-offs between various health programs for people with different health problems.

The importance for CEA of crafting a morally sound position on whom to ask should not be underestimated. One of the strongest responses that a society can make to particular parties who are disadvantaged by a social policy is to note that those parties themselves (or persons relevantly similar to them) have had a major role in the decision-making process that led to the policy in question. Conversely, defense of a policy decision is more difficult if those who bear its primary effects have not had notable input. The implications for the use of CEA are not hard to see. If in the process of discerning the critical values involved, CEA has queried people who can reasonably be construed to represent the patients in a category that ends up disadvantaged by resulting allocation, a ready response to critics is available.²⁰ If such people have not been queried, moral defense of the results—especially in a political context—will understandably be more difficult. CEA's moral and political future will be brighter if it can note precisely where in its process influential values have been contributed by representatives of those who are affected by final decisions. If that point is not at the elicitation of individual utility values (HRQoL), where will it be? It should not be at the level of societal values; there I have already explained the persuasive arguments for asking informed members of the general population. The only point left for eliciting specifically the values of patients is at the level of HRQoL.

The appropriate conclusion, I believe, is this: the societal values that CEA needs to explore if it is going to reflect the preferences that people actually have about these matters are properly elicited from representatives of the general population covered by the health plan(s) whose priorities will be influenced by the CEA being conducted, while individual quality-of-life ratings should be elicited from current or former patients.

IV. ‘Person Trade-Off’ Questions and the Inclusion of Self-Interest

What precisely, though, should representatives of the general public be asked to discern a social welfare function? The general answer is “PTO questions,” but that is not precise enough. There are numerous ways in which to couch such questions—three, at least.²¹ These can be illustrated with the comparison posed earlier between curative treatment for meningioma and lifesaving appendectomies (additional appendectomies, say, which result from an improved technique for detecting appendicitis):

PTO-Other. You are a member of the board of directors of a health authority for a region in which you do not reside. You have to choose between adding provision of the new treatment for meningioma (described in Section I) and improving the detection of life-threatening appendicitis. Annually, how many meningioma patients would have to be cured in order to make that quality-of-life improvement as valuable as the saving of ten lives with the improved technique for detecting appendicitis?

PTO-Self. You are selecting your health insurance plan. Plan A provides the new cure for meningioma while Plan B does not, but Plan A does not provide the refined detection technique included in Plan B that results in more lifesaving appendectomies. Consequently, Plan B is likely to save ten more lives a year from appendicitis than Plan A. You are as likely as the average enrollee to develop either condition. Thinking only in terms of what is best for you, how many patients do you say Plan A would annually have to cure of meningioma in order to leave you seriously undecided between it and Plan B?

PTO-Self & Other. You are a member of the board of directors of a health plan to which you yourself belong. The board has to choose between adding the new cure for meningioma and the improved technique for detecting appendicitis. You are as likely as the average enrollee to develop either condition. Considering both your own self-interest and what you think is best collectively for the plan’s membership, how many meningioma patients will have to receive the new cure for it to be as important in your eyes as the addition of ten lifesaving appendectomies?

Which type of PTO question is the most appropriate for eliciting societal value? An answer may significantly depend on one's normative theory of distributive justice. If the distributive justice that should morally govern health care significantly originates in contractarian considerations, either PTO-Self or PTO-Self & Other would seem more appropriate than PTO-Other. On the other hand, if defensible and substantive views of justice can derive from moral intuition or forms of ethical reasoning separate from consent or contract, then PTO-Other may be appropriate.

Are any other considerations, short of holding a clear view of the ultimate nature of justice, helpful in selecting which type of PTO question is most defensible? Some of the reasons for a contractarian direction in theories of justice may be particularly persuasive in the health policy context. On the one hand, moral intuition leads to sharply conflicting claims about moral justice in health care distribution. On the other hand, the dubiousness of utilitarian views of justice appears to be precisely what lies beneath the widespread disparity between health state utility ratings and PTO-elicited societal values. While contract or consent may have weaknesses in grounding adequate *general* theories of justice, consent to particular policies—and willingness to be bound by them—is unquestionably an important positive step in the achievement of a sense of fairness in making decisions with enormous negative repercussions for selected individuals. In an area of life where the stakes for an individual or family can be as high as they are in health care, and where moral struggle can be wrenching, consent can provide badly needed credence for any policies that emerge from it.

Thus, I would argue, PTO-Other is the first variety of PTO question that should be dropped as a candidate for the best device for eliciting health-related societal values. Which of the remaining two types of PTO question, though, is preferable? If the purpose of using PTO questions is to elicit something quite different from people than individual utilities, then PTO-Self & Other would seem preferable to PTO-Self. The latter is too close to TTO, SG, and other individual utility measuring questions. Thus, I would argue, PTO-Self & Other is the preferable device for eliciting health-related societal values.

V. The Importance of Understanding Patient Ratings of Individual Utility²²

To elicit societal values, we should then ask representatives of the general public PTO-Self & Other questions, but what information or understanding must those people have to be qualified respondents? If actual current or former patients are the proper source of individual health state utility ratings, then it will be important for representatives of the general public to understand and accept those ratings when they are responding to PTO questions for the subsequent measurement of societal value.

An important problem can arise at this point: biases about disability and illness can influence public representatives' elicited preferences about social value. Let me illustrate.

Table 2
**Hypothetical Utilities and Societal Values
 of Three Health States**

<u>Health Condition</u>	<u>Patient Estimate of Utility</u>	<u>Public Estimate of Utility</u>	<u>Unadjusted Public Estimates of Societal Value of Curing Condition</u>
Knee Osteo	0.9	0.8	0.05
Paraplegia	0.8	0.5	0.33
Quadriplegia	0.5	0.2	0.7

Table 2 shows hypothetical patient and public utilities for three health conditions—chronic knee impairment, paraplegia, and quadriplegia—and PTO responses from the public on the societal value of curing each of these three conditions. (The comparison standard is saving someone's life and returning them to full health, which as in all CEA models has a value of 1.0.) Patients' utility estimates could be measured by asking SG or TTO questions of people with chronic knee impairment, paraplegia, and quadriplegia, respectively. Public representatives' estimates of health-related utility could be measured by posing similar questions to them, asking them in the process to imagine that they had each of these three conditions. Societal value

measures could be obtained by asking appropriate PTO questions of representatives of the general public who have had the respective health states described to them and who are then asked how many people with these health states would have to be cured to equal the benefit of saving 10 patients' lives.

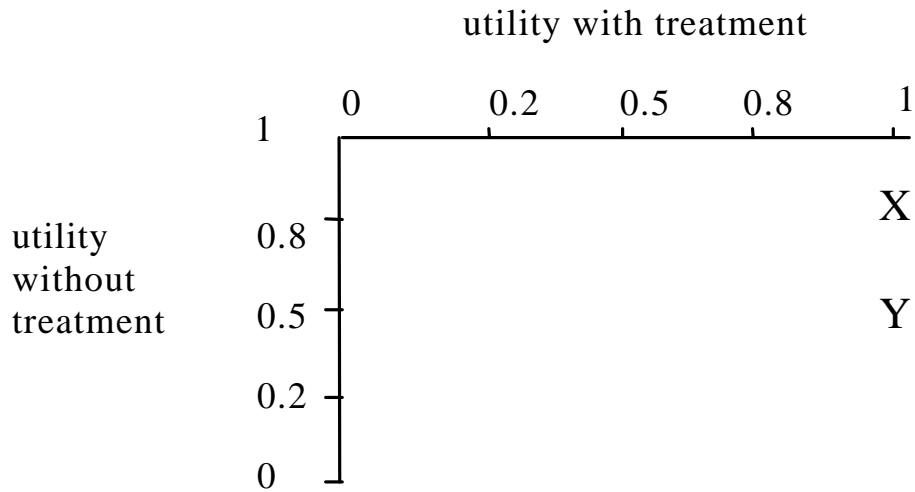
If patient utilities are used as the basis of societal value, then the benefit of curing paraplegia will be 0.2 (because it would improve people from 0.8 to 1). Note that in the hypothetical data presented, the societal value of curing paraplegia is expressed by public representatives as 0.33, not 0.2. (That is, the median response from the general public to a PTO elicitation was that the benefit of curing 30 people of paraplegia equals in value the benefit of saving 10 people's lives to perfect health.)

Now observe how serious the problem of biased views of individual utility can be when representatives of the general public express societal values. If patient and public estimates of the health related utility of specific conditions differ, how can we trust that societal values expressed by the public are based on accurate conceptions of the utility of treatment programs affecting the condition in question?

Figure 3, for example, shows two treatment programs, X and Y. Program X improves patients' average utilities from 0.8 to 1, whereas Program Y improves their average health related utility from 0.5 to 1. *Which program have representatives of the general public evaluated when they respond to a PTO elicitation on a treatment program curing paraplegia?* Since the utility of patients with paraplegia is 0.8, it may seem that the public has evaluated Program X, which improves patients from a utility of 0.8 to 1. However, the public thought paraplegia had a health related utility of 0.5. In that case, in *their* view, Program Y would represent a treatment program that cured paraplegia.

Figure 3

Two Treatment Programs with Undetermined Societal Value



Here, then, is the problem and why it is important. If we accept patients' estimates of their health related utility and combine this with public responses to PTO inquiries about curing paraplegia, we will conclude that treatment programs which improve people's health related utility from 0.8 to 1.0 have a societal value of 0.33, since the public said that saving 10 patients' lives was equally valuable as curing 30 people of paraplegia, which has a health related utility of 0.8. But when the public answered this PTO elicitation, they thought paraplegia had a health related utility of 0.5. It seems we have allowed the public's misperceptions about the quality of life of paraplegia (or any other health condition) to unduly influence their societal value responses. Should we not instead say that the societal value of curing paraplegia is what the general public would think it was *if they thought that it had an individual health state utility of 0.8* (the HRQoL that actual persons with paraplegia put on the condition)? The obvious answer to this (rhetorical) question should make clear how important it is that public respondents to PTO questions both understand what patients' utility ratings really are and accept those ratings as the quality of life that actually attaches to the health conditions at issue.

VI. The “Adaptation Problem”²³

At this point, however, a major objection to using health state utility ratings elicited from patients rears its head: the so-called problem of adaptation. When patients rate the quality of life in an impaired state more highly than the general public typically does, a large proportion of that difference may be due to the fact that people with long-term illnesses and disabilities have adapted to their impairing condition. (Adaptation includes such components as cognitive denial, skill enhancement, activity adjustment, substantive life-goal adjustment, lowered expectations, heightened Stoicism about life in general, and altered conceptions of health.) But then we may wonder: does adaptation make patients’ generally higher quality-of-life ratings of dubious value for purposes of resource allocation?

Doubts may be especially acute if adaptation is significantly comprised of cognitive denial, but moral doubts can arise even if adaptation does not reflect any cognitive or informational deficiency. One point of moral concern is the alleged similarity of patient adaptation with the adaptation of slaves—the “happy slave” phenomenon, which we do not allow slaveholders to distort into any argument that slavery might, after all, be relatively innocuous. Our concern is heightened, moreover, by the fact that the measured benefit we calculate to occur from curing a given condition will *diminish* insofar as patients adapt and rate their quality of life more highly than others would in that condition. Ironically, then, patients’ laudable adaptation to their circumstances may reduce the influence that their condition has in setting health care priorities.²⁴

I will not here take the time or space to pursue a remotely comprehensive analysis of the adaptation issue. I will instead pursue only two elements of such a discussion, both of which are particularly interesting philosophically: (1) Are representatives of the general public, imagining themselves to have a condition they are evaluating, *factually mistaken* if they do not believe they would ever adapt to it? Moreover, how is that issue of factual mistake related to what *evaluative privilege* actual patients might be seen to have viz-a-viz representatives of the general public? (2) How analogous to the objectionable “happy slave” phenomenon is patient adaptation?

1. Imagination, Factual Mistake, and Evaluative Privilege

What should representatives of the general public be expected to understand about the conditions they are comparing and evaluating? The general answer is that they should understand *the significant things about the health state that a patient actually experiences*. The further question, of course, is how much of the actual impact on real patients lives should be seen as the “significant” things that representative public respondents need to understand. Facts about patients’ typical adaptations, including adaptations to particular health states being evaluated, in addition to medical facts and social aspects?

Hypothetical patients will generally be making a factual mistake if they insist on using their own estimates of health state utility because *they* would never evaluate life with paraplegia at so high a level as persons with paraplegia do. A given individual, unusually focused on certain goals and activities that require leg power, could conceivably be factually correct in such insistence. Yet we are properly sceptical—and sceptical, no doubt, on the basis of actual empirical evidence about what happens to such insistent persons when they become paraplegic. To be sure, not all patients equally adapt, and there will be great variance in the valuations given by different patients. Still, most hypothetical patients would have little justification in insisting that they will not end up adapting. Therefore, if hypothetical patients are the proper parties from whom to elicit quality of life ratings, they should be informed of either the average facts of adaptation in regard to expressed quality of life, or the typical range of those facts. If they refuse to accept these prospective facts about themselves, it can generally be said that they have not understood the health state they are evaluating.

Must this limited point about how we should parse “factual mistake” drive us to use adapted patients’ values? Dan Brock has argued that there is still a legitimate difference in perspective even if hypothetical patients should be said to be making a factual mistake were they to imagine their later selves not then adapting.²⁵ Because the difference in perceived quality-of-life values stems from the patient becoming a “changed person,” Brock argues, we should not conclude that the hypothetical patient’s earlier evaluation was “mistaken.” Brock refers primarily to the role played in adaptation by adjusting one’s substantive goals. The disabled person’s “aims and values evolve in accommodation to that condition; he loses aims that are no

longer feasible and gains new feasible ones.” Were we as disabled persons to look back, we would “view ourselves as having become very different persons than we once were, but not having been mistaken in our earlier aims and values.” For Brock the correct conclusion is only that adapted patients have changed, not that they have corrected the *mistaken* aims and values of hypothetical patients. “The disabled person is in an *epistemically* privileged position with regard to facts about the experience of having his disability, but not with regard to how that condition should be *evaluated*” (my emphasis).

In part Brock is correct. As long as the hypothetical patient accepts the fact that, were she to accrue the condition in question, her values would very likely become those of an adapted patient, we cannot fault her with being “mistaken” or cognitively deficient when she still expresses different evaluations. Even though her evaluations are not “mistaken,” however, how could she defend the practice of continuing to evaluate the condition at her current, non-adapted level? After all, in most of her prospective years in a chronic condition, she will be espousing adapted values. Isn’t *that* the potentially real life that she is now supposed to be evaluating? Any life that she tries to imagine herself actually having, but as her current *non-adapted* self, is fictional, not just hypothetical, compared to her imagined life as an actual, likely-to-adapt patient. Why would she be trying to imagine herself as a *non-adapted* person with the condition, *a person whom she will very likely not be even if she does accrue the condition*? It is, of course, as a pre-adapted, hypothetical patient that she is now trying to evaluate the life of the real prospective person she would be with the condition, but the focus of the evaluation exercise is the life of a person who will actually have adapted values. Brock correctly notes that she will then be a changed person, but why does this imply that there is no difference in “epistemic privilege with regard to how that condition should be evaluated”? I would argue that the adapted patient is in a privileged position not only “in regard to facts about the experience of having her disability,” as Brock admits, but in the very enterprise—imagining what it would be like to be someone with the disability—that asking hypothetical patients inherently involves.

In summary, this is what can be said so far. (1) A hypothetical patient is factually mistaken if she imagines herself to have “the condition in question” but does not believe that she will ever adapt. (2) Even though the adapted patient is a “changed person” relative to her previous non-impaired self, the very task of now imagining herself to be an actual patient

requires her to imagine herself expressing values shaped by the adaptation that most patients undergo. While she cannot actually cease to be the non-adapted person she currently is, the force of the very activity of imagination pulls the hypothetical patient toward according the actual (and adapted) patient a great deal of evaluative privilege about individual health state utilities.²⁶

2. *Analogy with the “Happy Slave”*

This discussion of epistemic and evaluative privilege does not remotely conclude the normative argument about whether adaptation should disqualify actual patients from evaluating even individual health state utilities. It only establishes a prima facie case for using the patient’s perspective in that evaluation. Additional moral arguments can be lodged against using utilities shaped heavily by adaptation—for example, the analogy with the “happy slave,” the sadness of such accommodation, and the irony that the adaptation which will effectively diminish the value of curative treatments is often achieved with great and laudable effort.²⁷ Here I will pursue only the first of these arguments.

Christopher Murray²⁸ quotes a famous passage from Alexis de Tocqueville: “Should I call it a blessing of God, or a last malediction of his anger, this disposition of the soul that makes men insensible to extreme misery? Plunged in this abyss of wretchedness, the slave hardly notices his ill fortune; he was reduced to slavery by violence, and the habit of servitude has given him the thoughts and ambitions of a slave.”²⁹

The pull of the passage turns on the fact that slavery is a violent violation of the rights of individuals. If by our actions we push people into such depths of deprivation that they have to adapt to retain their self-esteem, and then if also, much to their credit, they actually adapt to a miraculous degree, it is appalling that we might turn around and claim that we have harmed them little. The great harm that forever remains, regardless of any amount of adaptation, is in the initial injustice. Only according to hedonistic utilitarianism, perhaps, would major injustice not be done. If one tried to measure the extent of the injustice through individual utility assessment, one would be grossly underestimating its extent.³⁰

What precedent, if any, might such an argument in the case of slavery carry for disease and disability? On the one hand, the two differ greatly in a significant respect: most disease and disability, unlike slavery, are caused by natural misfortune—or, at most, by *non-culpable* human negligence.³¹ There exist no unjust transgressors to even attempt perversely to remove the stain of their aggression by claiming that because of adaptation, patients have ultimately lost little well-being. In this respect, note that de Tocqueville starts off his passage with a reference to God, setting a context in which the reader already imagines a culpable agent. If we remove that element of a blameworthy agent from the picture—and presumably in the case of typical disabilities and chronic illnesses we should—in one important respect, at least, the analogy with slavery breaks down. In response to disease and disability we might keep thinking about the case of adapting to conditions of unjust enslavement, but that is mere mental association.

On the other hand, slavery may still be instructive. With disease and disability as well as with slavery, adaptation allows for a kind of negligence: the more people cope with their condition, the more we are able to ignore them. If we are obligated not to ignore them in the case of either slavery or disease and disability, then there can be culpable negligence in both cases. The cases of slavery and disease and disability remain different, however, in that the culpable injustice in the case of slavery occurs at the origin of the condition, not only in people's later reaction to it.

Thus at least one objection to the use of adapted patients' individual utility ratings, the analogy with slavery and the "happy slave," is weak. Pending further (and much needed) discussion, I conclude that the *prima facie* case for seeing the actual, adapted patient as the proper source of health related utility assessments stands unrefuted.

VIII. Conclusion

It is time that health care economics heed more carefully than it has heretofore the important distinction that economics more generally draws between individual utility and social value. If it does that, the philosophically narrow, exclusively utilitarian character of economic analysis will be broadened, and certain acute problems of discrimination about lifesaving will

abate. While at Stage 1 of analysis the discernment of individual health state utilities should remain a very significant component of CEA, that discernment should be supplemented by a Stage 2 analysis in which health-related societal values are empirically measured. These interpersonally comparative values should be elicited from representatives of the general public by PTO questions—particularly PTO-Self & Other questions. Those respondents, moreover, should understand and accept patients' ratings of quality of life with the health conditions in question and not use the ratings they believe they would hold were they to obtain these conditions. The "adaptation problem" complicates this last judgment, but not enough to justify failing to elicit patients' ratings of health state utility as the appropriate ratings for representatives of the general public to understand and to use at Stage 2 in generating estimates of societal value.

END NOTES

- ¹ Hereafter I shall generally use “societal” rather than “social” value, though the latter tends to be the standard term in the economics literature. “Social,” unfortunately, includes a colloquial sense related to cultural and interpersonal relationships that may carry an unwitting impression short of full seriousness. Also hereafter, I shall use “community” to include simply an aggregate of persons, not only true communities.
- ² The examples here are the same as those used by Peter Ubel, George Loewenstein, Dennis Scanlon, and Mark Kamlet, “Individual Utilities are Inconsistent with Rationing Choices: A Partial Explanation of Why Oregon’s Cost-Effectiveness List Failed,” *Medical Decision Making* 16 (1996), pp. 108-116.
- ³ Considerable portions of this section derive from Paul Menzel, Marthe Gold, Erik Nord, Jose-Luis Pinto-Prades, Jeff Richardson, and Peter Ubel, “Toward a Broader View of Values in Cost-Effectiveness Analysis of Health,” *Hastings Center Report* 29, no. 3 (1999), pp. 7-15.
- ⁴ Technically this characterizes, not CEA generally, but a subdivision called “cost utility analysis” (CUA). In CEA generally, effectiveness may be measured either in terms of particular study-specific natural units (e.g., cases of a disease averted) or in terms of a total health spectrum encompassing metric like QALYs. In our ensuing use of “CEA” we will actually be referring to CUA. Such linguistic practice is not uncommon in North America; it is less common in Europe. On these distinctions as well as the Healthy Year Equivalent (HYE) alternative to the QALY as a common unit of measurement, see Michael F. Drummond, Bernie O’Brien, Greg L. Stoddart, and George W. Torrance, *Methods for the Economic Evaluation of Health Care Programmes*, 2nd Edition (Oxford: Oxford University Press, 1997), pp. 139-143 and 176-183. On another QALY alternative, the Disability Adjusted Life Year (DALY), see Christopher J.L. Murray and Arnab K. Acharya, “Understanding DALYs,” *Journal of Health Economics* 16: 6 (December, 1997), pp. 703-730.
- ⁵ For a more detailed explanation of the questions discussed in this paragraph, see Drummond, O’Brien, Stoddart, and Torrance (note 4), pp. 151-156, and Marthe Gold, Donald L. Patrick, George W.

Torrance et al., "Identifying and Valuing Outcomes," in Marthe Gold, Joanna Siegal, Louise B. Russell et al., eds., *Cost-Effectiveness in Health and Medicine* (New York: Oxford University Press, 1996), pp. 110-119.

⁶ Technically, in the sense of classic, cardinal utility, only SG and TTO are measures of utility. VAS gives only ordinal rankings.

⁷ Erik Nord, "The QALY—A Measure of Social Value Rather Than Individual Utility?" *Health Economics* 3 (1994), pp. 89-94.

⁸ Constructed from data obtained by Ubel et al., "Individual Utilities are Inconsistent with Rationing Choices..." (note 2). For related findings see Erik Nord, Jeff Richardson, and K. Macarounas-Kirchmann, "Social Evaluation of Health Care Versus Personal Evaluation of Health States: Evidence on the Validity of Four Health State Scaling Instruments Using Norwegian and Australian Surveys," *International Journal of Technology Assessment in Health Care* 9 (1993), pp. 463-478, and Jose-Luis Pinto Prades and Angel Lopez Nicolas, "More Evidence on the Plateau Effect: A Social Perspective," *Medical Decision Making* 18 (1998), pp. 287-294.

⁹ In claiming that conventional CUA is deficient in its treatment of the value of care in the face of death, I am by no means agreeing with those who would inflate the value of life to an absolute. People are, in fact, perfectly and knowledgeably willing to trade some lifesaving for other health services. Yet at the same time, the value that a wide range of public opinion puts on lifesaving care in the face of death appears to be inadequately captured by conventional economic analysis.

¹⁰ The term "health-related social welfare function" is used by Paul Dolan, "The Measurement of Individual Utility and Social Welfare," *Journal of Health Economics* 17: 1 (1998), pp. 39-52.

¹¹ This very question about potential for discrimination was at the heart of part of the controversy surrounding the plan for prioritizing health services developed by the state of Oregon; see Paul Menzel, "Oregon's Denial: Disabilities and Quality of Life," *Hastings Center Report* 22, no. 6 (1992), pp. 21-25. On the empirical matter of just what are our beliefs about equal or non-equal values of lifesaving to different levels of health, one study has revealed distinct preference for equivalence in the value of lifesaving to full health and the value of lifesaving to moderate chronic pain and dependence on crutches: Erik Nord, "The Relevance of Health State after

Treatment in Prioritising Between Different Patients,” *Journal of Medical Ethics* 19 (1993), pp. 37-42. Another relevant study leaning in the same direction is found in Nord, “Health Politicians Do Not Wish to Maximize Health Benefits,” *Journal of the Norwegian Medical Association* 113 (1993), pp. 1171-73. Respondents were asked to compare two illnesses, both equally common and involving the same degree of suffering, whose preferred treatments were equally costly. The preferred treatment for illness A helps patients a little, and the preferred treatment for B helps a lot. Knowing that an increase in funding can cover treatment of only the patients with one of these illnesses, not both groups, choose between two different allocations: (1) Most of the increase should be allocated to treatments for illness B, since the effects are greater. (2) The increase should be divided evenly between the two groups, on the grounds that they are equally entitled to treatment. Almost half of the respondents (48%) chose the second (egalitarian) view, while 24% chose the first. See additional discussion in Nord, “Health Status Index Models for Use in Resource Allocation Decisions,” *International Journal of Technology Assessment in Health Care* 12: 1 (1996), pp. 31-44. I am not suggesting that empirical data would reveal preference for equal lifesaving value if one of the conditions in the comparison was so severe that many people thought it was possibly no better than death (persistent vegetative state, for example).

For a philosophical, not empirical, discussion which concludes that quality of life differences are seldom relevant in trade-off lifesaving, see Frances M. Kamm, *Morality, Mortality*, vol. I, *Death and Whom to Save From It* (Oxford University Press, 1993), pp. 255-260. For discussion of the discrimination issues in particular that are at stake in such contexts, see David Hadorn, “The Problem of Discrimination in Health Care Priority Setting,” *JAMA* 268: 11 (16 September 1992), pp. 1454-1459, and Philip G. Peters, Jr., “Health Care Rationing and Disability Rights,” *Indiana Law Journal* 70: 2 (spring 1995), pp. 491-547.

¹² Paul T. Menzel, *Strong Medicine: The Ethical Rationing of Health Care* (Oxford University Press, 1990), p. 84.

¹³ This figure of speech and the two visual figures that follow are modified from those used in Peter Ubel, Erik Nord, Marthe Gold, Paul Menzel, Jose-Luis Pinto-Prades, and Jeff Richardson, “Improving Value Measurement in Cost-Effectiveness Analysis” (in submission).

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- ¹⁴ Norman Daniels, “Distributive Justice and the Use of Summary Measures of Population Health Status,” in Institute of Medicine Committee on Summary Measures of Population Health, *Summarizing Population Health: Directions for the Development and Application of Population Metrics* (National Academy Press, 1998), pp. 58-71 at 66-67, and Daniels and James Sabin, “Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers,” *Philosophy and Public Affairs* 26: 4 (fall 1997), pp. 303-350 at 336-340.
- ¹⁵ Andrew Edgar, Sam Salek, Darren Shickle, and David Cohen, *The Ethical QALY: Ethical Issues in Healthcare Resource Allocations* (Haslemere, UK: Euromed Communications, 1998), at 75-76, 90, and 92.
- ¹⁶ Most of this section is revised from portions of Menzel et al., “Toward a Broader View...” (note 3), and Peter Ubel, Jeff Richardson, and Paul Menzel, “Societal Value, the Person Trade-Off, and the Dilemma of Whose Values to Measure for Cost-Effectiveness Analysis,” *Health Economics* (forthcoming).
- ¹⁷ Many studies on both sides of this issue are cited by the U.S. Public Health Service Panel: Gold et al., “Identifying and Valuing Outcomes” (note 5), p. 100. The Panel later recommends using general public representatives for what it calls the “reference case” of CEA, a structure that is still likely to be CUA without the incorporation of societal values.
- ¹⁸ See Menzel et al., “Toward a Broader View...” (note 3), pp. 12-13. The same authors have articulated the two-stage model of CEA that separates HRQoL assessments at the level of individual utility from societal value judgments in more detail in a paper written primarily for health economists: Erik Nord, Jose-Luis Pinto-Prades, Jeff Richardson, Paul Menzel, and Peter Ubel, “Incorporating Societal Concerns for Fairness in Numerical Valuations of Health Programs,” *Health Economics* 8 (1999), pp. 25-39. A key advantage for any model that separates HRQoL from societal value judgments is avoiding the problem of discrimination about lifesaving discussed in the previous section and more extensively in Ubel et al., “Improving Value Measurement...” (note 13).
- ¹⁹ See, e.g., the summary of the literature on variations in quality-of-life ratings as a function of the difference in perspective between patients and non-patients by Christopher J.L. Murray, “Rethinking DALYs,” in Murray and Alan D. Lopez, *The Global Burden of Disease: A*

Comprehensive Assessment of Mortality and Disability from Diseases, Injuries, and Risk Factors in 1990 and Projected to 2020 (World Health Organization and Harvard University Press, 1996), pp. 1-99 at p. 29. For a specific study revealing that those currently in poor health rank the HRQoL of their condition higher than inexperienced respondents do, see Paul Dolan, “The Effect of Variance of Illness on Health State Valuations,” *Journal of Clinical Epidemiology*, 49: 5 (May, 1996), pp. 551-564. Other studies in this same direction are D. G. Froberg and R. L. Kane, “Methodology for Measuring Health State Preferences,” *Journal of Clinical Epidemiology* 42: 6 (1989), pp. 585-92; R. L. Kane, R. M. Bell, and S. Z. Riegler, “Value Preferences for Nursing Home Outcomes,” *Gerontologist* 26 (1986), pp. 303-8; and D. L. Sackett, G. W. Torrance, “The Utility of Different Health States as Perceived by the General Public,” *Journal of Chronic Diseases* 31 (1978), pp. 697 - 704.

²⁰ This may not constitute the strongest form of defense, the *consent* of those disadvantaged. For explication of that stronger response, which undoubtedly is more difficult to sustain, see Paul Menzel, *Strong Medicine* (note 12).

²¹ Adapted from Jeff Richardson and Erik Nord, “The Importance of Perspective in the Measurement of Quality-Adjusted Life Years,” *Medical Decision Making* 17 (1997), pp. 33-41.

²² This section is adapted from Ubel, Richardson, and Menzel, “Societal Value...and the Dilemma of Whose Values to Measure...” (note 16).

²³ My discussion here derives from a longer paper on the adaptation issue that is currently in process: Paul Menzel, Paul Dolan, Jan Abel Olsen, and Jeff Richardson, “Adaptation to Disability and Disease and the Problem of Perspective in Health State Valuation.”

²⁴ Adaptation’s potential to reduce the influence of disabled and chronically ill patients’ impairments takes several possible forms. If adaptation is relatively uniform across all illnesses, the case for quality of life improvements may be given less weight generally, relative to the case for improvements in length of life. On the other hand, if those suffering from some conditions adapt much more than others, the former may lose out to the latter as well as to other patients who stand to gain life extension. In either case, we may be attracted to erasing adaptation’s indirect influence on priority setting by eliciting HRQoL ratings not from patients but from a representative sample of the general public.

²⁵ Dan W. Brock, “Justice and the ADA: Does Prioritizing and Rationing Health Care Discriminate Against the Disabled?” *Social Philosophy and Policy* 12, no. 2 (1995), pp. 159-185, at 182-184.

²⁶ At this point this is a *prima facie* judgment. Other arguments, such as the one that follows, create the possibility that the evaluative privilege should be neutralized or even reversed.

²⁷ The fuller range of these arguments is pursued in Menzel et al., “Adaptation...” (note 23).

²⁸ Christopher J. L. Murray, “Rethinking DALYs,” (note 19), p. 31.

²⁹ Alexis de Tocqueville, *Democracy in America* (New York: Anchor Books, originally 1839). The “happy slave” phenomenon is ripe with still more ironies. Edmund Morgan, in a review of Philip Morgan on 18th century slavery in the Chesapeake region of the U.S., notes that “where slavery was more oppressive, as in South Carolina [not the Chesapeake], slave culture was stronger, more African, more autonomous” and the slaves ironically perhaps happier. The reviewer elaborates further: Moreover, “as [Philip] Morgan points out, while the formation of their own culture was in itself ‘the most significant act of resistance’ by slaves, yet ‘by creating an autonomous culture, slaves also eased the torments of slavery, and, in that respect, their cultural creativity created accommodation.’ Autonomy could thus help to perpetuate the torments of subjection.” See Edmund S. Morgan, “The Big American Crime” [review of five books on U.S. slavery, including Philip D. Morgan], *New York Review of Books*, December 3, 1998, pp. 14-18, and Philip D. Morgan, *Slave Counterpoint: Black Culture in the Eighteenth-Century Chesapeake and Lowcountry* (Chapel Hill: University of North Carolina Press, 1998).

³⁰ This is somewhat different than the argument that Amartya Sen makes in *Inequality Reexamined* (Cambridge: Harvard University Press, 1992), at pp. 6-7, 54-55, and 149-150, which he terms the objectionable fact of “deprivation and reduced aspirations.” Sen sees this problem as plaguing both utilitarianism and any social philosophy that focused on equality of welfare. My discussion here is only of the more specific “happy slave” phenomenon, not Sen’s more general “deprivation” objection.

³¹ At least not very culpable—in any case, not remotely as culpable as those who enslave others are for the active and overt step of enslavement.