

## **Towards a Broader View of Values in Cost-Effectiveness Analysis of Health Care**

Paul Menzel, PhD (Pacific Lutheran University)

Marthe R. Gold, MD, MPH (School of Medicine, City University of New York)

Erik Nord, PhD (National Institute of Public Health, Oslo)

Jose-Luis Pinto Prades, PhD (Universitat Pompeu Fabra, Barcelona)

Jeff Richardson, PhD (Centre for Health Program Evaluation, West  
Heidelberg, Australia)

Peter Ubel, MD (Center for Bioethics, University of Pennsylvania)

Written with support from the Rockefeller Foundation and with assistance from Fundacion BBV (Barcelona). For their helpful comments the authors wish to thank Philip G. Peters, Jr., reviewers for the *Hastings Center Report*, and editor Bette-Jane Crigger.

Key Words: cost-effectiveness analysis, QALYs, health economics, ethics, fairness, discrimination.

Correspondence to: Paul Menzel, Office of the Provost  
Pacific Lutheran University  
Tacoma, WA 98447  
[menzelpt@plu.edu](mailto:menzelpt@plu.edu)  
fax 253-535-8760, ph 253-535-7126

## I. Introduction.

Cost-effectiveness analysis in health care (CEA) is designed to tell decision makers how much health benefit is likely to be produced by different investments. It does much more than compute the net monetary costs of health care interventions and programs. It expresses effectiveness in common units of health-related value such as Quality Adjusted Life Years (QALYs) that allow the benefits of lifesaving and life improving treatments to be quantified on the same scale of measurement.<sup>1</sup>

The work CEA can do is indeed remarkable. It can take programs with qualitatively very different outcomes—lifesaving dialysis and quality-enhancing hip replacements, for example—and inform us of their costs in relation to their respective *comparable* effects (their QALYs). This ability to compare disparate effects is one of several respects in which CEA is the child of utilitarian welfare economics. In that larger discipline, too, a huge range of values gets collected into one common and measurable notion, “utility.” Moreover, welfare economics’ conception of “value to society” is typically built up out of individuals’ utilities, combined in some way. In all of these respects—its one scale of value, its quantifying of that value, and its combining of individual pieces of value into aggregate wholes for society—conventional health economics is what one would expect a specialty within economics to be.

How does CEA in health care obtain its single metric of value for comparing widely different effects? Typically three factors are incorporated. The first, and by far the most complex conceptually, is *the size of the quality improvement* produced by treatment: the saving of life and its maintenance at a certain subsequent level of health-related quality of life (HRQoL), or the improvement of HRQoL for people not facing life-threatening illness. We

will refer to this as the “size of treatment effect.” It is here that mortality and morbidity are compared and 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 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 of quality-of-life eliciting questions are used by different practitioners of CEA. In the “Time Trade-Off,” for example, respondents (who may be people with or without experience of the condition being evaluated<sup>2</sup>) may be asked how many of an anticipated 20 remaining years of their lives with a specific health condition they would be willing to sacrifice in order to obtain its complete cure. Suppose that on average their answer is 4—that is, 20 percent of the remaining time they would otherwise live. Then they have rated the quality of life in that state of health at 0.8, a 20 percent reduction from 1.0.

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 CEA incorporates and combines these factors by simple multiplication 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 beneficiaries. (Hereafter we refer to this structural type of CEA as “conventional CEA.”) For example, if hip replacements generally raise recipients’ HRQoL from 0.8 to 0.98, effectively last 10 years, and cost \$18,000 each, they typically produce 1.80 QALYs at a cost of \$10,000/QALY. If a year of in-patient hemodialysis typically costs \$32,000 and saves a life of 0.8 health-related quality, it produces 0.8 QALY at a cost/QALY of \$40,000. In a situation where not all of the medical demand for these two procedures is being met, these numbers would suggest that the production of

health would be maximized most efficiently by investing new funds in additional hip replacements rather than in expanding dialysis.

The quantified effects used in CEA are classic expressions of a form of “utility”—what might be called “health related utility.” While CEA is technically a descriptive analysis that does not by itself tell decision makers to maximize health-related utilities such as QALYs, the CEA enterprise by its very nature reveals which categories of health care investments will maximize them. Utilitarianism is its philosophical parent. It is thus not surprising that conventional CEA provokes many of the same ethical objections that plague utilitarianism in general: inadequate attention to the individual person in relationship to the aggregate good, and insensitivity to issues of distributive justice involving the least advantaged. One might, of course, simply dismiss CEA because of the weaknesses of the utilitarian philosophy that it currently reflects, or one might continue to use it while becoming pointedly aware of its limitations. We will urge, however, an alternative: to examine specific values that conventional CEA fails to incorporate with an eye toward reforming the methodology of CEA itself.

Included among the factors that conventional CEA currently disregards or underestimates are the initial severity of illness from which a treatment produces an improvement, any unique value of lifesaving or treatment in the face of death, the fact that patients’ limited potential for increased health may be a long-term identifying characteristic of their lives, and age (age itself, as distinct from the association of age with duration of effect). Consequently, important social values of justice and non-discrimination can stand starkly at odds with recommendations emerging from CEA. This exposes CEA to not only ethical but

political attack—what politician wants to defend policies which expose individual people to injustice in the name of an impersonal, aggregate good? Suppose, however, that such social values could be incorporated into the very model that CEA studies would use. Health economics might then see its ethical sensitivity improve, and perhaps its political fortunes, too.

*The central proposal we make in this paper is that the field of CEA should begin to explore how social values might be better incorporated into the “effectiveness” side of economic analysis so as to strengthen the ethical argument for using CEA as a major tool for resource allocation.* We first describe one of the clearest ethical factors that is currently not adequately accounted for in CEA, severity of illness, and two other factors that spark public controversy about CEA, treatment in the face of death and limitation of health potential. Then we proceed to discuss four additional factors which, if also taken into account, could increase the credibility of CEA for use in allocative decision making. Finally, we turn to a related ethical issue that has not been satisfactorily resolved in conventional CEA, the issue of whom to ask to determine the utility values before and after a change in someone’s HRQoL.

These matters inevitably constitute a delicate conversation between two separate perspectives, economics and bioethics, each with markedly different sets of analytical tools. It is vital that bridges be built between them. No field reckons more directly with “nasty” and value-loaded trade-offs than health economics. And while bioethics has seldom rushed to confront its issues with much awareness of the realities of scarce financial resources, it customarily wrestles openly with multiple values and the tensions between them. Philosophically inclined bioethicists should not shun the discipline of economics, and

economists should become accustomed to wrestling with challenges to their allegedly limited evaluative horizons.

In this dialogue it is important that participants with either perspective recognize the importance of the questions asked from the other perspective. Several of the ethical factors and societal values that we will discuss have already been noted—and a few pursued—in the CEA literature. The U.S. Public Health Service Panel on Cost-Effectiveness in Medicine, for example, explicitly noted the public preference for priority treatment of those in poor health (the special attention that should be given to the severity of a patient’s initial condition).<sup>3</sup> Our goal here is to pursue the analysis of such values more explicitly and systematically, as well as to suggest the possible systematic inclusion of such factors in CEA itself.

Although some of the factors we discuss may affect the so-called “individual utility” dimension of economic analysis, they are mainly relevant when “societal value” is being calculated. In societal value, the focus 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 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, as distinct from the “admission” or “bedside” level (where many feel that such interpersonal trade-offs should not be dealt with numerically). We will repeatedly speak of societal values that conventional CEA, we believe, either inadequately measures or misses entirely.

We will sometimes refer to such values as “ethical factors.” When we do, we are speaking of an aspect of treatment whose omission from consideration in allocative decision making can be objected to on ethical grounds. This is a more demanding notion than

“preference” or unexamined “value.” For the omission of a factor to be ethically objectionable, one has to be able to articulate some argument for the preferences it generates, not merely point out that people hold those preferences. We articulate such arguments for the relevance of the severity, lifesaving, and level-of-potential factors in Section II and for some of the other factors in Section III. When we speak only of “societal/social values” without also referring to them as “ethical factors,” we are usually less sure that a coherent moral justification can currently be given for them. The line between a societal value that we refer to as an ethical factor and one that we do not, however, is not firm. Notable moral argument can be made against the paternalism or anti-democratic character of ignoring the preferences about allocation of health care that a population actually holds (assuming that those preferences are not irrational or ethically objectionable—as they are, for example, when they reflect discriminatory attitudes). Thus, the relevance to CEA of all the “societal values” that we discuss, not only the “neglected ethical factors,” is arguably an ethical matter.<sup>4</sup>

## II. Three Neglected Ethical Factors to Incorporate into Cost-Effectiveness Analysis

1. *Severity of Illness.* Conventional CEA incorporates the severity of the illness that a procedure treats only insofar as it is one of the two variables needed for determining the size of the treatment effect—the difference between initial and post-treatment health. It does not accord any weight to the severity of illness per se—the initial HRQoL. Both public official statements and population preference data, however, suggest that people often wish to give greater priority to those who are worse off before treatment, above and beyond the priority they achieve within CEA by any gain in HRQoL from treatment.<sup>5</sup>

For example, in a study of 150 Norwegian politicians accountable for health policy at the county level, subjects were presented with a dilemma: provide treatments for a severe illness A that would bring “a little” help, or treatments for a moderate illness B that would help “considerably.” They had three choices: divide resources evenly between the two illnesses and their treatments, allocate most to illness A (the most severe), or allocate most to B. Nearly half (45%) chose equal division, and 37% chose priority for A. Only 11% chose priority for B.<sup>6</sup>

The key to severity’s ethical relevance is captured by the fact that inherently, treating the more severely ill is helping those who are in greater need. Notable treatises in social philosophy have articulated a fundamental general priority for helping “the worst off”—those whose life prospects make them the most disadvantaged.<sup>7</sup> We also reduce inequality if we give priority to patients with more severe illness. For example, if two treatments can raise one person’s HRQoL from 0.5 to 0.9 and another’s from 0.3 to 0.6, effectively treating the less severe illness leaves a greater difference between the two persons’ health states (0.3 and 0.9). Effectively treating the more severe illness reduces inequality of health and leaves the two individuals with respective HRQoL values of 0.5 and 0.6.

The empirical data suggesting an independent concern for severity would thus appear to have an ethical basis. To be sure, critics might challenge the data itself. Did the study respondents really understand the hypothesized treatment effect to be smaller for those whose initial illness is more severe? Perhaps respondents accord extra priority to the most severely ill not because they see them as more ill, but because they believe that the increments in individual utility obtained from treatment are actually larger than those accruing to those whose baseline health is better. One study, however, used examples that conveyed particularly

clearly to respondents that the more severely ill were benefiting from smaller treatment effects; it, too, yielded distinct preference for giving priority to those with the more severe illnesses.<sup>8</sup>

While the matter needs more empirical study, it would surely be dogmatic for health economists to insist that if respondents do in fact give priority to patients whose initial HRQoL is lower, it must be because they see them as gaining individually greater benefits. Moreover, their rejection of the independent importance of severity would be particularly unreasonable given that this social value has some sound ethical justification.

2. *Lifesaving and Treatment in the Face of Death.* The most severe illnesses, of course, put people face to face with death. The propensity to regard situations where identifiable patients face great risk of avoidable death as holding a unique call on resources has been called the “Rule of Rescue.”<sup>9</sup> Rooted in the Kantian tradition of considering the individual to whom one is relating as an ultimate end-in-herself, this “rule” resists the usual quantitative aggregation of economic analysis. Conventional CEA has conducted its business as if this propensity could be ignored—or at least, as if it was not the sort of factor that CEA could account for as part of the measurable value of different outcomes. This stance damages the credibility of health economics. Critics such as Hadorn, for example, have argued that “any plan to distribute health care services must take [this Rule of Rescue] ... into account if the plan is to be acceptable to society.”<sup>10</sup>

We are inclined to agree with Hadorn. Societal action provides ample evidence that we will expend great effort and large resources to avert death (the girl down the well, astronauts in space, sailors lost at sea, etc.). We also have examples from public life such as the state of Oregon, where all lifesaving services rose to a separate high priority category in the state Medicaid plan’s eventual rationing list.<sup>11</sup> Several systematic studies provide

corroborating evidence that people place a special value on care in the face of death that has a plausible prospect of success.<sup>12</sup>

A relatively simple thought experiment illustrates the intuitive power of lifesaving's value in the face of the contrary calculations of conventional CEA. 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 "time trade-off" responses in which persons with paraplegia themselves expressed a willingness to sacrifice 20 percent of their remaining life extension to obtain a complete cure of their condition. Conventional CEA would then recommend saving the first group, who can be returned to full health, before saving an equal number in the second group. It would recommend shifting priority to the paraplegia group only if the number of lives saved there at similar cost was at least 20 percent greater than the number of persons saved and returned to normal health. Yet few among us, reflecting seriously about the value of continuing to live, honestly believe that it is less important for society to save the lives of persons with paraplegia than the lives of others.<sup>13</sup> The value of lifesaving appears to overwhelm the influence of the differences in HRQoL on which conventional CEA focuses.

This example also reveals that lifesaving and treatment in the face of death pose particular concerns with respect to issues of discrimination against the disabled and the chronically ill.<sup>14</sup> In conventional economic analysis the value of saving lives can be influenced by whose lives, of what quality, they are. The disabled and the chronically ill will of course

resist any such influence on valuations, and for good reason if we examine more carefully the implications of HRQoL judgments. Suppose, again, that the disabled person has ranked her individual quality of life at 0.8. This willingness to accept a 20 percent shorter remaining life in order to be cured from a permanent disability does not in any way indicate that she thought that her *life*, in relation to the prospect of *death*, was any less valuable and important to save than *another* fully healthy person's life.<sup>15</sup> While one number may have two meanings, we cannot take it for granted that it has; here, in fact, the 0.8 that expresses willingness to trade time within a life does not constitute a comparative judgment about the value of saving different persons' lives.

To be sure, this point about the potential for discrimination in the conventional model of CEA must not be overstated. The lifesaving interventions or programs being assessed in CEA rarely pertain selectively to a disabling condition such as paraplegia, so that discrimination against chronically ill and disabled people may be far less present in the actual use of CEA than one would surmise from its theoretical model.<sup>16</sup> Still, it is not a sufficient defense of conventional CEA to argue that, serendipitously, disabled patients rarely have life-threatening diseases or conditions requiring separate lifesaving treatments. First, such separate diseases and treatments can and do occur—an example would be HIV disease, for which there are HIV-specific medications. Second, rationing can indeed occur by medical categories of patients within the scope of a treatment, not just by an entire treatment. For example, chronic pulmonary disease patients might be poorer candidates for coronary artery bypass grafts than patients with normal lungs (and therefore, in carefully crafted practice guidelines, be excluded from such surgery).<sup>17</sup> Third, an allocation model's potential for discrimination against the disabled is hardly rendered irrelevant by probable pragmatic

realities if conceptually the model's implications are sharply at odds with society's values about discrimination.<sup>18</sup>

In any case, consideration for the special value of treatment in the face of death pertains to more than lifesaving services. Widespread attitudes toward hospice and other non-lifesaving terminal care also suggest the same special value of care in the face of death. Putting up with severe pain for a six-month period when one expects to live for many years is one thing; having to put up with it at the end of one's life is another. People generally, not just patients facing death, have a special concern that life not end in pain. Thus, palliative measures for patients with terminal conditions produce an extra value than what palliative measures of nominally equal effectiveness produce for other patients.<sup>19</sup>

In claiming that conventional CEA is deficient in its treatment of the value of care in the face of death, we are 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 care in the face of death appears to be inadequately captured by conventional economic analysis.

3. *Level of Health Potential.* The societal value of priority for more severe illnesses focuses independently on a patient's start point, as distinct from the size of treatment effect. Analogously, the end point may have independent relevance which is not accounted for in the calculation of the size of the treatment effect. We shall call this the "level of potential" factor, which is directly related to people's reluctance to disadvantage patients who are already burdened with lower potential for overall health.

This value has been operative in the paraplegia lifesaving example discussed above, but it speaks to many more cases than the lifesaving at issue there. To take the broader, non-lifesaving case, suppose that on a utility scale, treatment can improve one group of people from 0.6 to 0.8 and another from 0.6 to 1.0, and that the first group's end point of 0.8 represents its members' maximum prospective health potential. Should we really regard the second group's treatment effect as having twice the value of the first's? Treatment can, after all, "fully cure" even those in the first group within the perspective of each of their lives. That health potential defines, in significant part, the lives they can lead, and since a life with that potential is the only life that they in any case will have, it is plausible to think that reaching their 0.8 level counts as notably more than half the value of other people's improvement from 0.6 to full health.

The essential ethical claim here is that where people are "located" in life in relation to their maximum realistic potential is an important factor to take into account in the context of resource allocation. In part this may be a function of aversion to inequality: the gap between the 1.0 for one person and the 0.6 for another that is likely to result from giving priority to treatment for illness B over A is larger than the gap between 0.8 and 0.6 that is likely to result from treating A before B. With more empirical research, other moral elements besides aversion to inequality may come to light as involved in the societal preference for compensating for the downward pressure of low end-state potential in net "effectiveness."

The same study of Norwegian politicians that has previously been mentioned in connection with severity of illness also provides suggestive empirical support for the level of potential factor.<sup>20</sup> The respondents were given another dilemma. Two illnesses, both equally common and involving the same degree of suffering, have treatments that are equally costly.

The best treatment of illness A helps patients a little, and the best treatment of illness B helps a lot. With an increase in funding that can cover treatment of only the patients with one of these illnesses, not both groups, respondents were asked to 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 (48%) chose the second (egalitarian) view, while 24% chose the first.

Admittedly, the currently available public preference data are less clear in confirming consideration for limited level of health potential as an important societal value than in confirming the importance of severity of illness. They still, however, appear to conflict with the way that health potential is considered in conventional CEA.<sup>21</sup> Moreover, the ethical relevance of special consideration for level of long-term health potential can be powerfully articulated.

### III. Other Values with Promise for Inclusion in CEA

While the severity of illness, care in the face of death, and limited level of health potential may be factors most clearly connected to significant societal values about the distribution of health care, they are not the only ones. A discussion of various other factors will indicate the range of values that an expanded model of CEA might include.

4 and 5. *Maintenance of Hope and Assurance of Treatment.* Conventional CEA views societal benefit as directly proportional to the gain in health utility produced by treatment and this, in turn, as a linear function of the average improvement in HRQoL and the number of

people benefited by such outcomes. At least two factors may qualify this simple linear relationship between numbers of people and total value.

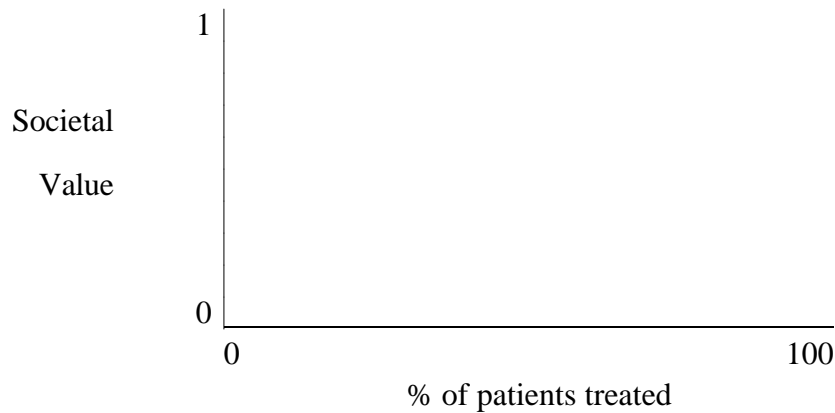
*Maintenance of Hope.* Suppose we can allocate resources to one program that will yield a certain level of beneficial outcome for a greater number of people, or to another that generates the same individual outcome but for a smaller number (though the number of people *treated* is just as large). The efficient allocation—as presently judged by CEA—would be to devote all of the resources to the former. Several studies, however, reveal that many people wish to preserve the hope of treatment for everyone; to accomplish this, they are willing to devote some resources to those in the “inefficient” treatment category.<sup>22</sup> Were those public preferences to be heeded, a smaller number would be helped, at no higher average level of benefit than a larger number could have been.

*Assurance of Treatment.* Evidence is also available that many people prefer extending entitlement for a treatment from some to all in a disease or treatment category even when such extension is inefficient.<sup>23</sup> They may consider it inequitable to exclude some people from treatment that most others receive, regardless of the decrease in marginal benefit if treatment is extended to all. Moreover, incomplete coverage within a category may give rise to feelings of uncertainty—feelings that are themselves disutilities, though not focused on health benefit.

Maintenance of hope and assurance of treatment have an interesting relationship. They appear at opposite ends of a spectrum in which the percent of patients treated in a relevant illness category moves from 0 to 100. Maintenance of hope creates a disproportionate benefit as the first patients are treated. Assurance of treatment creates its disproportionate benefit at the other end of the spectrum, as a program approaches full coverage of its patient

population. (See Figure 1.) If these two factors both bear up under further empirical investigation, aggregate value will turn out to be a non-linear function of the probability that a person in that medically appropriate population will receive treatment.

Figure 1



The implication is that to maintain hope we might provide inefficient services to a few patients in some illness categories rather than to none at all (as long as they were selected by a sufficiently fair procedure). In other cases we might offer a treatment to everyone in an illness category despite the diminished odds of cost-effective outcomes for those added at the margin. In either case, we will have gone against the outcome-efficiency orientation of conventional economic analysis.

Considerably more study is needed before we would urge the inclusion of these preferences for maintenance of hope and assurance of treatment in a more comprehensive view of CEA. Such research should be undertaken. Available evidence already suggests that the practice of treating total value as directly proportional to the number of people effectively treated does not satisfactorily reflect people's values.

6. *Duration Discounting.* Conventional CEA takes duration into account in a strictly proportionate fashion—by multiplying the value of one year of a treatment effect by the number of years for which the effect lasts, with one important additional step: each year past the first is discounted for time preference back to its present value.<sup>24</sup> Empirical studies, however, suggest a different pattern in people’s valuations of the importance of duration—perhaps a different pattern when they are evaluating different potential durations in their own lives, and very likely a different pattern when they consider duration in the context of interpersonal comparisons.

In interpersonal comparisons, for example, respondents in Australia thought that saving 10 people for 10 years each would be equivalent to saving 7 people for 20 years each.<sup>25</sup> That is, it took 140 total years accumulated in 20-year spans to equal in value 100 total years accumulated in 10-year spans, a reduction of 57% in the average value of a year of life in the last 10 years of each 20-year span.<sup>26</sup>

There are at least three possible reasons for such discounting beyond the pure time-preference used in conventional economic analysis. (a) At the level of individual utility, a “quantity-effect” may obtain that is similar to diminishing marginal utility generally: because of the benefits already achieved, the last year of life in a ten-year span of experience is not seen to be as valuable as any one of the earlier years (or certainly not the first). (b) At the level of societal value, people may have an aversion to inequality that leads them to value duration less than proportionately. Assuming their rough equivalence of age, it seems more equitable to extend two persons’ lives for ten years each, for example, than one person’s life for twenty. (c) Also at the level of societal value, the level-of-potential factor may be

associated with duration; the 10 year extension, in contrast to the 20 year extension, will accrue to patients with shorter life potential.

Regardless of which explanations are supported by future research, it appears safe to say that to adequately capture people's values, CEA will need to discount the value of longer spans of life or health gained more than it already does as a result of pure time preference. Health economics needs to embark on a wide range of future studies of duration, keeping pure time preference of the individual distinct from the other elements which may arise in social values. Such empirical research will hopefully reveal the relative importance of these different elements in people's discounting of the value of longer durations of health benefit. Moreover, not only the size of the total discount but the ethical arguments for its use need to be investigated and debated.<sup>27</sup> One possible outcome from such research is the acceptance of the relevance of duration discounting for some reasons but its rejection for others.

7. *Age.* While duration is directly accounted for in conventional CEA (though perhaps not correctly), the related factor of age per se is not directly taken into account at all. Indirectly, of course, it is, as treatments for the relatively elderly often produce benefits of shorter duration than treatments for the relatively young, thereby making treatments of the young productive of more life-years than treatments of the elderly. In addition to this indirect effect of age, however, there is notable evidence that comparisons in which duration of gain is held equal while age is varied reveal preferences considerably at odds with conventional CEA's disregard of age per se. Many would probably say that more than one 70-year-old would have to be saved for 10 years to equal the value of saving one 30-year old for 10 years. Moreover, this preference persists when one rids respondents of any implicit presumptions that quality of life between 70 and 80 must be lower than that between 30 and 40.<sup>28</sup>

The primary moral grounds for this preference for the young are undoubtedly egalitarian. Just as the most severely ill should be treated first, even when their benefit from treatment may be smaller, so also the young should be treated first, even when their gain is smaller, so that they obtain a fairer and more equal chance of living a long life.<sup>29</sup> There may, of course, be societies in which the elderly are so revered that these egalitarian considerations for at least some favoring of the young get overridden. In those contexts, conventional CEA-recommended allocations that effectively ignore age per se would not be out of step with public preferences. For societies that do not have such strong differential reverence for the elderly, however, they would be.

Societal values that contradict conventional CEA treatment may give rise to charges of “ageism.”<sup>30</sup> Perhaps, in fact, the societal issues are so contentious that empirical investigation will show little in the way of any predominant social value toward greater priority for the young than is already indirectly accorded by CEA. In any case, however, the conventional treatment of age by CEA—assuming that age is relevant only through its indirect and highly variable effect on the duration of treatment effect—is questionable on both moral and empirical grounds. More research is warranted.<sup>31</sup>

*Other Influential Factors.* Undoubtedly there are other factors typically omitted from CEA which people consider relevant to interpersonal social value: personal responsibility, citizenship and nationality, compensation for those who are disadvantaged in non-health dimensions of their lives, health effects on others, non-health effects on others, the degree of either personal or community control seen to be preserved by a given program, etc. We only note these other factors here. Without more suggestive empirical data or persuasive ethical

justification, we do not recommend that they be placed on the research agenda of items for possible inclusion in a more sophisticated conception of CEA.

#### IV. Implications for Another Ethical Issue in CEA: Whom to Ask

Important ethical issues are also present in a longstanding controversy within CEA over who should be asked to rate individual HRQoL, patients and ex-patients who have had the conditions being rated, or the general public. In quantifying an improvement in HRQoL, conventional CEA has primarily—and appropriately—focused not on any objective health increment that would be difficult to construe as *value*, but on the subjective value or utility of the gain. Often, though, CEA has then proceeded to measure that subjective value—here it is at the level of individual utility—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 primarily affected by the policies it influences.

We suggest that including societal values along with individual health utilities presents the opportunity for an ethically more adequate resolution of this whom-to-ask issue. A strong case can be made for eliciting *societal* values from representatives of the general public, but preference input at this level needs to be kept distinct from input at the level of individual utility and HRQoL ratings. This implies—or at least suggests—a two-part model for CEA.<sup>32</sup> In the first part, individual utilities would be elicited from patients and ex-patients. In the second part, interpersonal trade-off preferences, based in part on knowledge of affected people's individual utilities, would be elicited from representatives of the community. Once the use of input from community representatives is secure at the level of societal value, we will argue, the case for asking patients and ex-patients at the level of

individual utility becomes stronger. Were this to become accepted practice, CEA could more adequately respond to cogent objections from patient groups that their values have not been considered.

Asking one party rather than another might well be significant. It is not uncommon for ratings by patients of their own HRQoL—especially those by chronically ill patients—to be higher than ratings of the same health states by those who have not directly experienced them.<sup>33</sup> Admittedly, the empirical evidence is 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.<sup>34</sup> Notably, though, no studies reveal patient ratings that are *lower* than those expressed by non-patients. Thus the balance of current evidence still points toward a difference.<sup>35</sup>

In any case, the underlying moral issue remains. As noted, CEA claims to be measuring the *value* of the real effects of health care, not just effects in some descriptive sense. 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?

Undoubtedly other matters, both practical and theoretical, complicate this thorny issue.<sup>36</sup> The question needs to stay open. Our emphasis here is to claim that distinguishing

social value from individual health utility changes the larger context in which the whom-to-ask debate takes place. At the level of “societal value” focused on *interpersonal* trade-offs, the *prima facie* ethical case favors consulting representative people in the group or society served by the health care system in question. One reason is the “insurance principle”: if people determine the final value of insured services only after they know of their particular need for these services, they may inflate that value and take unfair advantage of all the others in the society, who are providing most of the necessary financial resources.<sup>37</sup> The resultant strong argument for eliciting *societal* values from a representative sample of the larger society or insurance pool, however, provides little justification for eliciting *HRQoL* ratings from community representatives. At the latter, individual utility level of measurement, the *prima facie ethical* case favors asking patients and ex-patients the questions from which tables of *HRQoL* ratings are constructed.

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.<sup>38</sup> 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 affected by final decisions. If that point is not at the elicitation of individual utility values (HRQoL), where will it be? At the level of societal values, we have already decided that informed members of the general population should be asked.

The appropriate conclusion, we believe, is this: while the societal values that we urge CEA to explore incorporating would seem to be properly elicited from representatives of the general population, *prima facie* ethical argument favors eliciting HRQoL ratings from current or former patients wherever possible. Those who wish to elicit even HRQoL ratings from the general public need to provide more persuasive ethical arguments for their view.

## V. Conclusion.

We have emphasized the importance of social values as distinct from individual utilities. Despite the clear recognition in economic theory that individual utility may be affected by other people's well-being, many economists pay little attention to this in practice and even less attention to the possibility that social welfare may involve values that cannot be explained by individual utilities, however these are combined.<sup>39</sup> We do not by any means believe that individual utilities are irrelevant, but we do claim that their almost exclusive emphasis in much applied economic research is not justified in the health sector. This relative disregard of distributive issues is often rationalized on the grounds that maximizing the value of output leaves open the possibility of redistributing income in such a way that no one will be worse off and some will remain better off,<sup>40</sup> and that it is then the responsibility of governments to take care of this subsequent distribution. As has been recognized by virtually all health economists, however, it is often not possible to redistribute health—or even other goods to compensate for

it. To take the clearest case, it is difficult (to say the least!) to compensate anyone who has died as a result of one program having been given priority over another. Largely because of such difficulties of compensation, interpersonal decisions about health care should certainly not be aimed solely—and perhaps not even primarily—at maximizing individual utilities. If societal values are not taken into account at the start, serious ethical questions about fairness and discrimination go unaddressed.

Some will undoubtedly believe that it would just be best to leave societal values entirely out of the CEA enterprise, relegating quantitative analysis to the very limited task of conveying information about individual utilities. Economist Alan Williams, however, has correctly argued that the great deficiency of that approach is that it leaves considerations of equity floating without any conception of *how* important they should be. Then they either get used as trump cards, without regard to what amount of individual health utility is sacrificed for them, or they get ignored because “there is no way of establishing what bearing, if any, those [equity] principles actually had upon the [decision making] outcomes.... [If the latter is the case] it is tempting to conclude that the rhetoric [of equity] is not matched by any real commitment to do anything effective.... The quest for greater quantification of equity considerations seems worth pursuing on those grounds alone, despite the hostility it is likely to engender from those who mistakenly equate precision with lack of humanity.”<sup>41</sup>

CEA in health care should broaden its conception of the array of values that might be accounted for in the “effectiveness” side of its ledger, adding societal values to the mix. If and when empirical research and ethical analysis of selected societal values reveals them to be clear, quantifiable, of sufficient societal importance, and not irrational or ethically

discriminatory, the structure of CEA should be adjusted to allow for their inclusion.<sup>42</sup> To be sure, any such modification of CEA's structure to include societal values must be pursued carefully, to avoid a situation where expanded quantification creates an illusion of specificity and importance not justified by what we actually know of societal preferences and their ethical foundations. Nevertheless, it is time for health economics to recognize the relevance of these values and the ethical issues to which they speak. It is also time for bioethicists to assist with the considerable task of discerning them in as precise and usable a form as possible.

---

NOTES

<sup>1</sup> Technically this characterizes, not CEA generally, but a subdivision called “cost utility analysis” (CUA). In CEA generally, effectiveness may be measured in terms of either particular study-specific natural units (e.g., cases of a disease averted) or one of the totally encompassing metrics like QALYs. CUA refers to analysis which only uses an encompassing metric. In this paper, however, we will use “CEA” to refer to what is actually CUA, a not uncommon practice in North America. On these distinctions see Michael F. Drummond, Bernie O’Brien, Greg L. Stoddart, and George W. Torrance, *Methods for the Economic Evaluation of Health Care Programmes*, 2<sup>nd</sup> Edition (Oxford: Oxford University Press, 1997), pp. 139-143 and 176-183. For an important variant of the QALY, the DALY (Disability Adjusted Life Year), see Christopher J.L. Murray and Arnab K. Acharya, “Understanding DALYs,” *Journal of Health Economics* 16: 6 (December, 1997): 703-730.

<sup>2</sup> We pursue that choice in Section IV.

<sup>3</sup> Louise B. Russell, Marthe Gold, Joanna Siegel, Norman Daniels, and Milton Weinstein for the Panel on Cost-Effectiveness in Health and Medicine, “The Role of Cost-Effectiveness Analysis in Health and Medicine,” *JAMA* 276: 14 (October 9, 1996): 1172-1177, especially at 1176. The book-length report is Marthe R. Gold, Joanna Siegel, Louise B. Russell, and Milton Weinstein (eds.), *Cost-Effectiveness in Health and Medicine* (New York: Oxford University Press, 1996).

<sup>4</sup> An extremely important question is whether societal values discerned by empirical preference studies ought to be used when distributive matters with such high stakes are at issue. Norman Daniels has argued for openly deliberative, “political” procedures to generate those values instead of using empirical data directly. See 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. A related view, but one more supportive of QALYs, is the recommendation to incorporate “discourse ethics” into the process of eliciting preferences

---

made by Andrew Edgar, Sam Salek, Darren Shickle, and David Cohen in their European Commission funded study, *The Ethical QALY: Ethical Issues in Healthcare Resource Allocations* (Haslemere, UK: Euromed Communications, 1998), at 75-76, 90, and 92. In this paper we are not proposing direct use of empirical data on societal values without public deliberation. We only note some of the data at variance with QALY maximization and articulate the values such data seem to represent.

<sup>5</sup> For public commission statements about the priority of severity, see Norwegian Commission for Prioritizing in Health Care, *Retningslinjer for Prioritering Innen Helsevesenet (Guidelines for Prioritizing in Health Care)*, NOU 1987: 23 (Oslo: Universitetsforlaget, 1987); Core Services Committee (of New Zealand), *Core Services for 1995/1996* (Wellington: Ministry of Health, August 1994); Dutch Committee on Choices in Health Care, *Choices in Health Care* (Rijswijk: Ministry of Welfare, Health, and Cultural Affairs, 1992); and Swedish Health Care and Medical Priorities Commission, *No Easy Choices: The Difficulties of Health Care*, SOU 1993: 93 (Stockholm: The Ministry of Health and Social Affairs, 1993). For studies of population preference data, see Erik Nord, "The Trade-Off Between Severity of Illness and Treatment Effect in Cost-Value Analysis of Health Care," *Health Policy* 24 (1993) 227-238; Erik Nord, J. Richardson, A. Street, P. Singer, and H. Kuhse, "Maximizing Health Benefits vs. Egalitarianism: An Australian Survey of Health Issues," *Social Science and Medicine* 41 (1995): 10: 1429-1437; and Peter Ubel, D. Scanlon, G. Loewenstein, and M. Kamlet, "Individual Utilities Are Inconsistent with Rationing Choices: A Partial Explanation of Why Oregon's Cost-Effectiveness List Failed," *Medical Decision Making* 16 (1996): 2: 108-119.

<sup>6</sup> Erik Nord, "Health Politicians Do Not Wish to Maximize Health Benefits," *Journal of the Norwegian Medical Association* 113 (1993): 1171-1173.

<sup>7</sup> The most famous one in the 20<sup>th</sup> century is undoubtedly John Rawls, *A Theory of Justice* (Harvard University Press, 1971). Norman Daniels develops a Rawlsian approach to health care in *Just Health Care* (Cambridge University Press, 1985). Many others similarly speak in terms of protecting the least well-off, e.g., Charles J. Dougherty, *Back to Reform: Values, Markets, and the Health Care System* (Oxford University Press, 1996).

<sup>8</sup> Erik Nord, "Health Politicians. . .," note 6.

- 
- <sup>9</sup> Albert Jonsen, "Bentham in a Box: Technology Assessment and Health Care Allocation," *Law, Medicine and Health Care* 14 (1986): 172-174.
- <sup>10</sup> David Hadorn, "Setting Health Care Priorities in Oregon: Cost-effectiveness Meets the Rule of Rescue," *JAMA* 265: 17 (May 1, 1991): 2218-2225.
- <sup>11</sup> David Hadorn, "Setting Health Care Priorities. . . ," note 10.
- <sup>12</sup> Erik Nord, J. Richardson, 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): 463-478, and Jose-Luis Pinto Prades and Angel Lopez Nicolas, "More Evidence on the Plateau Effect: A Social Perspective," *Medical Decision Making* 18: 3 (July-September 1998): 287-294.
- <sup>13</sup> Few studies have investigated whether this claim is reflected in empirical preference data. One that found confirming data is Erik Nord, "The Relevance of Health State after Treatment in Prioritising Between Different Patients," *Journal of Medical Ethics* 19 (1993): 37-42. For a philosophical 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.
- <sup>14</sup> Such concerns receive extensive discussion by David Hadorn, "The Problem of Discrimination in Health Care Priority Setting," *JAMA* 268: 11 (16 September 1992): 1454-1459, and Philip G. Peters, Jr., "Health Care Rationing and Disability Rights," *Indiana Law Journal* 70: 2 (spring 1995): 491-547.
- <sup>15</sup> Paul T. Menzel, *Strong Medicine: The Ethical Rationing of Health Care* (Oxford University Press, 1990), p. 84.
- <sup>16</sup> See Louise Russell, et al. (1996), note 3 above, at 1175.
- <sup>17</sup> David Orentlicher, "Rationing and the Americans with Disabilities Act," *JAMA* 271: 4 (January 26, 1994): 308-314 at 310.
- <sup>18</sup> In two companion papers, we explain how a two-stage model of CEA that separates HRQoL assessments at the level of individual utility from societal value judgments avoids precisely this problem of discrimination about lifesaving. One paper, written primarily for health

---

economists, describes in some detail an actual model of a reformed CEA. The other, for a more general audience, integrates the former paper's description of an economic model with the current paper's ethical focus. The former is 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* (forthcoming, 1999). The latter is Peter Ubel, Erik Nord, Marthe Gold, Paul Menzel, Jose-Luis Pinto Prades, and Jeff Richardson, "Improving Value Measurement in Cost-Effectiveness Analysis" (in submission). On the larger context for proposing a two-stage model, see Erik Nord, *Cost-Value Analysis in Health Care: Making Sense of QALYs* (Cambridge University Press, August 1999).

<sup>19</sup> The general point here has been made by John Harris, "QALYfying the Value of Life," *Journal of Medical Ethics* 13 (1987): 117-123.

<sup>20</sup> Erik Nord, "Health Politicians. . . ," note 6. See also data in Nord, "The Relevance of Health State after Treatment. . . ," note 13, and in Nord, "Health Status Index Models for Use in Resource Allocation Decisions," *International Journal of Technology Assessment in Health Care* 12: 1 (1996): 31-44.

<sup>21</sup> In addition to the previous reference, see Erik Nord, et al., "Maximizing Health Benefits vs. Egalitarianism. . . ," note 5.

<sup>22</sup> P. Ubel and G. Loewenstein, "The Efficacy and Equity of Retransplantation: An Experimental Survey of Public Attitudes," *Health Policy* 34 (1995): 145-151, and E. Nord and J. Richardson, "Who Cares About Cost? Does Economic Analysis Impose or Reflect Social Values?" *Health Policy* 34 (1995): 79-94.

<sup>23</sup> P. Ubel, M. DeKay, J. Baron, and D. Asch, "Cost-Effectiveness Analysis in a Setting of Budget Constraints: Is It Equitable?" *New England Journal of Medicine* 334 (1996): 1174-1177.

<sup>24</sup> Pure time preference is the discounting element reflected in the lower value that people place on a given benefit (for example, a year of life) that occurs ten years from now as compared to now. While time-preference discounting of health benefits is more controversial than time-preference discounting costs and monetary benefits, the general practice in the established models of cost-effectiveness analysis is to discount both. For discussion, see J. Lipscomb, M.C. Weinstein, and G.W. Torrence, "Time Preference," pp. 214-146 in Marthe Gold, et al. (1996), note 3.

- 
- <sup>25</sup> Erik Nord, Andrew Street, Jeff Richardson, Helga Kuhse, and Peter Singer, "The Significance of Age and Duration of Effect in Social Evaluation of Health Care," *Health Care Analysis* 4: 2 (May 1996): 103-111, at 107.
- <sup>26</sup> The discounting of the value of the last 10 years of each 20-year span relative to 10-year spans is much higher than the 29% aggregate reduction in value (140 to 100). Presumably each of the first 10 years of the seven 20-year spans is equivalent in value to one of the 10-year spans. Therefore the last 10 years in the 20-year group (70 years total) equal in value just the remaining 30 of the aggregate years in the 10-year group. That is a 57% reduction.
- <sup>27</sup> Frances M. Kamm, *Morality, Morality*, vol. I (note 13), pp. 237-248.
- <sup>28</sup> Erik Nord, et al., "The Significance of Age. . .," note 25. See also J. and P.O. Johannesson, "The Economics of Aging: On the Attitude of Swedish People to the Distribution of Health Care Resources Between the Young and the Old," *Health Policy* 37 (1996): 153-161, and the several studies cited and discussed by Aki Tsuchiya, "Age-Related Preferences: Should Health Benefits be Age Weighted?" (unpublished, Department of Economics, Kyoto University).
- <sup>29</sup> This is the "fair go" or "fair innings" argument articulated by John Harris, *The Value of Life* (London: Routledge & Kegan Paul, 1985).
- <sup>30</sup> DALYs (see note 1) use a form of age weighting that may be particularly contentious. See Sudhir Anand and Kara Hanson, "Disability-Adjusted Life Years: A Critical Review," *Journal of Health Economics* 16: 6 (December, 1997): 685-702. The conception of age weighting suggested by our discussion is different.
- <sup>31</sup> For an analysis that argues for a separate consideration of age accomplished by quantified "age-weights," see Alan Williams, "Intergenerational Equity: An Exploration of the 'Fair Innings' Argument," *Health Economics* 6: 2 (March-April, 1997): 117-132.
- <sup>32</sup> For more detailed articulation of such a model, particularly in relation to severity of illness and compensation for limited health potential, see Erik Nord, et al., "Incorporating Societal Concerns. . .," note 18.
- <sup>33</sup> 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): 551-564.

<sup>34</sup> Many studies on both sides of this issue are cited by the U.S. Public Health Service Panel: Gold, et al. (1996), note 3, p. 100. The Panel later recommends using general public representatives for what it calls the “reference case” of CEA.

<sup>35</sup> Erik Nord, Xavier Badia, Montserrat Rue, and Harri Sintonen, “Hypothetical Valuations of Health States Versus Patients’ Self Ratings,” *EUROQOL Plenary Meeting Discussion Papers* (Barcelona, October 3-6, 1995), citing also numerous other studies.

<sup>36</sup> One complication is the debatable moral relevance of patients’ adaptation to the realities of chronic illness; see Dan Brock, “Justice and ADA: Does Prioritizing and Rationing Health Care Discriminate Against the Disabled?” in *Social Philosophy and Policy* 12 (1995): 159-84. Another is differences of perspective in preventive as opposed to acute care contexts; in the former the initial patient is not afflicted with the condition being prevented. See other considerations in M. Gold, D.L. Patrick, G.W. Torrance, D.G. Fryback, D.C. Hadorn, M.S. Kamlet, N. Daniels, and M.C. Weinstein, “Identifying and Valuing Outcomes,” in Gold, et al. (1996), note 3, pp. 82-134, at 98-106.

<sup>37</sup> Allen Gibbard, “The Prospective Pareto Principle and Equity of Access to Health Care,” in the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Securing Access to Health Care, II* (Washington, DC, 1982), 153-178. Cited in David Hadorn, “The Problem of Discrimination...,” see note 14.

<sup>38</sup> 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 15.

<sup>39</sup> Welfare economics has traditionally accounted for such equity considerations by estimating “inequality aversion” parameters. It is interesting that though such a practice is firmly rooted

---

in traditional economics, it is relatively foreign to conventional CEA. A few leading health economists, however, have gone to notable lengths to incorporate non-utilitarian social values into their work. See, for example, Alan Williams, note 31.

<sup>40</sup> This is the so-called Kaldor-Hicks or “potential Pareto optimality” criterion.

<sup>41</sup> Williams, note 31, at pp. 120 and 128.

<sup>42</sup> For an illustration of such structural adjustment, see Nord, et al., “Incorporating Societal Concerns for Fairness...,” note 18. A very different manner of including social values in economic analysis is represented by Alan Williams’ treatment of age-weights, note 31.