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A Critique of Oregon's Prioritization
of Health Services under Medicaid

By

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THESIS

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I. Introduction: Medicaid and Cost Containment

Given the limitations that Americans are willing to spend to finance health care for the poor, state governments have sought ways to limit health care expenditures while still providing some basic level of coverage. The principal mechanisms used to this aim have been to raise the eligibility requirements for coverage under the state and federally funded Medicaid program, and to limit the reimbursements for services provided by the program. The result of these attempts has been to produce a growing population of medically indigent people and shrinking group of providers who are willing to bear the cost of their under-reimbursed care. Many states have begun to address the dual problem of uninsured citizens and under-reimbursed care that these cost containment strategies have engendered. Most have attempted find alternate sources of funding to provide services for those without insurance. In addition, some states have experimented with mandating employers to either provide health insurance to their employees or contribute through taxation to their coverage under an expanded state administered program.

What these approaches do not address, however, are those factors in health care financing that have driven up costs to a level to where the affordability of insurance has become an issue. Among these factors, the expansion of available therapies and services, and the introduction of new technologies over the past twenty-five years since the inception of Medicaid in 1965, have played a significant role in the rising costs. Because of the third-party payment, newly introduced therapies have historically been

reimbursed with little concern over relative increases in cost and effectiveness. As a result, costs have mounted in the face of a dearth of reliable information about the value of most medical therapies. Efforts at cost containment in health care have generally sought to reduce expenditures without consideration of the value of the services that are being purchased. The reasoning behind this approach can be understood in light of the paucity of available data on effectiveness and the difficulty in assessing what is valuable in health care.

Nonetheless, some authors feel that cost containment efforts will ultimately fail in America unless there is a mechanism by which to control the growth of costs attributable to technology.¹ Underlying this concern about changes in technology is the presumption that more available services means that more services will be consumed. More significant, however, is the concern that the marginal value of these increased costs is shrinking; that the improvements in health produced by cost-raising technology are increasingly difficult to justify.

It was in this environment of expenditure limits and doubt toward the value of costly technology that Oregon joined a small group of states in 1987 which had decided to limit funding under Medicaid for organ transplantation. Increasingly unable to meet all of the health needs of all the poor, these states had made a first step toward limiting expensive life-saving, and thus arguably 'necessary,' care instead of further limiting the

¹ Schwartz WB. The inevitable failure of current cost-containment strategies: Why they can provide only temporary relief. *Journal of the American Medical Association* 1987; 257:220-224.

number of people eligible for Medicaid coverage. The political fallout of this value-laden decision resulted in legislation in the state of Oregon, proposing to explicitly examine the issue of cost and benefits of medical treatments reimbursed under Medicaid. This approach involves evaluating the relative value of health care services provided by Medicaid, prioritizing those services, and establishing a set of benefits which will be offered to all people below 100% of the Federal Poverty Line. The legislation thus attempts to increase access while maximizing the value of the care purchased for this population given a limited budget.

This proposal to explicitly limit care that is provided under Medicaid based on the relative value of services represents a monumental departure from past American health policy. It threatens to shatter the American myth that all Americans deserve to receive all beneficial health care that is technically available. It is a myth that distinguishes us in our minds from those civilized countries which 'ration' health care through waiting lists, limiting access to new technology, and bureaucratic interference. In the rhetoric of rationing, it would be inhumane to deny such basic human needs as health care, in the absence of a dictating wartime necessity. For many of the poor in this country, however, a guerilla war has been ongoing: one that has no front, only nameless victims and faceless perpetrators. State budget cuts for health services across the country have devastated the poor's access to quality health care, and made rationing a daily occurrence in the United States. Thus the objections to the Oregon plan arise not simply from a stance against limiting care, but from the public's discomfort toward a rationing scheme which is explicitly elaborated.

Oregon's proposal to trade comprehensive coverage for full access under Medicaid promises to offer a solution to problems of assuring access to health benefits given budgetary limitations, which if it proves successful, may set a precedent to be followed by other states. It is an undertaking that has been shunned by many because of its complexities. It raises questions about how we place value on health care, what the government's obligations are in the protecting the health of its citizens, and who is to make these decisions. Oregon's priority-setting legislation proposes one set of answers to these question. These answers, far from being definitive, tend to underscore the difficulties that such fundamental questions beget. Oregon's transformation of a community-forged set of "Principles for Health Care Resource Allocation"² into the list of priorities to derived by cost-benefit analysis³ illustrates the difficulty that an operational assessment of value in health care presents. This paper offers a critical examination of the theoretical and practical problems in the formulation and implementation of Oregon's proposal to prioritize health care services.

² Adopted by the Citizens Health Care Parliament, September 23-24, 1988, Portland , Oregon. Reproduced in "Quality of Life in Allocating Health Care Resources," Oregon Health Decisions, December 1988.

³ Oregon Health Services Commission, Preliminary Report, March 1, 1990.

II. Background: Crisis in Oregon's Medicaid Program-- Coverage vs. Access

While most states have had to reconcile the difference between a available revenues and escalating expenditures for health care in the 1980's, Oregon's plight has been more severe for several reasons. Oregon is one of the few states in which voters have passed legislation that limits state revenues and expenditures. The state constitution prohibits bonded indebtedness to finance public services, and requires a balanced budget. Oregon's tax base is limited as the state has no sales tax. In addition, the state has been slow relative to other states to recover from the national recession of 1981 to 1985. While the nation's non-agricultural employment opportunities grew by 13.2% between 1980 and 1987, Oregon's opportunities grew only 4.7%. Oregon's gross state product rose by 36.6% from 1980-86, compared with a growth of 57% in the nominal gross national product over the same years. Despite its limited monies, the legislature had hopes of improving access to basic health care for low-income Oregonians as the 1987-89 biennium legislative session began.⁴ Even though some monies would be available from savings outside of health care services, as well as from the annual allowable budgetary increases, it was soon recognized that other health expenditures would have to be eliminated in order to meet constitutional limits on expenditures. It should be noted that the Legislature decided not to tamper with these constitutional

⁴ Welch GH and Larson EB. Dealing with limited resources: The Oregon decision to curtail funding for organ transplantation. *New England Journal of Medicine* 1988; 319: 171-3.

limits despite a predicted \$400 million state surplus for the 1987-89 budget cycle.

In the spring of 1987, the Governor and Legislature had singled out organ transplantation, excluding kidney and corneal transplants, as a likely target for budgetary cutting. Kidney and corneal transplants were spared because of reimbursement of the former under Medicare, and the relatively small expenditure necessary to sustain the latter. The decision to target organ transplantation was based on both its costliness and limited success in Oregon. The first transplantation that was funded by the state of Oregon was performed in 1985, when a girl underwent two liver transplants, at a cost of \$150,000, and subsequently died.⁵ Nineteen transplants were funded between 1985 and 1987, at a cost of \$1 million; only nine of those patients were still alive as of 1987.⁶ The cost of follow-up care for each survivor was calculated to be \$24,000 per year. In addition, these expenditures were expected to increase. The Division of Adult and Family Services projected that 34 patients would need transplants during the 1987-89 biennium at a cost estimated at \$2.2 million. In turn, this cost was expected to double in the following two years.

Federal guidelines for Medicaid mandate that patients funded under the program must receive "equal treatment for similarly situated patients." As a result, proposals to limit the number of transplants funded by the state to a budgeted level were not viable. While other states had limited coverage for

⁵ Id., p.171.

⁶ Adult and Family Services Division, Department of Human Resources, State of Oregon. Oregon Medicaid organ transplant services. For public presentation November 20, 1987. Revised March 6, 1988.

transplantations under Medicaid by formulating explicit selection criteria, as required under federal statute, the Division of Adult and Family Services pointed out that denial of coverage had the potential to be contentious and highly politicized. As part of their presentation to the Legislature, the Division urged that a decision be made between providing the expensive transplants for a few or using that money to expand basic medical services to a greater number of Oregonians. The Joint Ways and Means Committee voted unanimously on June 1, 1987 to end coverage for organ transplantation, with no public debate on the subject. In its place in the budget, the Committee substituted basic medical coverage for about 1,500 low-income children and pregnant women. Several weeks later, the new budget was passed by the Oregon House and Senate by significant margins (47 to 7 and 19 to 3, respectively).

Public reaction

Despite the prior denial of two transplants, the policy eluded widespread public criticism until November 1987, when the media publicized the story of a seven-year-old boy, Coby Howard, who was denied a bone marrow transplant for acute lymphocytic leukemia. The regional hospital in Portland that was to perform the operation required \$70,000 prior to surgery. Denied by the state authorities, the boy's family appealed to the public for funds. Fund-raising drives brought in \$30,000 before Howard died in December 1987. Howard's death received national attention as the media decried the need of children to become actors to raise the money needed to avert death. Meanwhile, another private fund-raising effort for a 17-year-old in the more community-oriented city of Bend, Oregon was successful through an intense series of charitable events. Neighboring states

took notice as some families fled with their children to states like Washington, where transplant funding is available and residency requirements are lenient.⁷ The public response since has included numerous fund-raising drives for others needing transplants, as well as two lawsuits, and a boycott of organ donations by some low income citizens.⁸

The high visibility of those denied transplants has kept the issue in the public eye. The public debate centered on issues of the fairness of singling out those in need of organ transplantation as targets for budget cuts. The 'all or none' basis of such a decision was also at issue, particularly since it was felt that some patients could have clearly benefitted more than others from the procedure. More central to the issue of Medicaid financing was the point made by those seeking funding for transplants, who argued that the decision to curtail funds for a particular treatment appeared arbitrary and unreasonable when other procedures of more questionable effectiveness and value, such as coronary bypass operations, consumed significantly more state funds.⁹ Several reasons have been proposed to explain why organ transplantation has been selected out of the large number of high-cost procedures which are currently funded through Medicaid.¹⁰ Organ transplantation represents a high visibility, costly procedure, which benefits only a select few. In addition, it is a relatively new therapy, and as such is less difficult to forgo than those treatments which are entrenched in the

⁷ Paulson T. Leukemia-stricken child brought to state in bid to save life. *Seattle Post-Intelligencer*. April 5, 1988:A4.

⁸ O'Neill P. State sets tone for far-reaching transplant fight. *Oregonian*. January 31, 1988: C1, C6.

⁹ Crawshaw R and Hines B. Organ transplants: A search for health policy at the state level. *Western Journal of Medicine* 1989; 150, 3: 361-3.

¹⁰ Welch HG and Larson EB. p.173.

budgets of health care providers, as well as in the minds of consumers as standard care. Furthermore, coverage for organ transplantation is not mandatory under Medicaid rules, and as a discretionary expenditure for states, it is a target for cost containment. These factors suggest that new therapies which do not replace more costly older therapies are likely to be targeted in the future. New budgetary expenditures, like organ transplants in Oregon, will become increasingly difficult to justify in the zero-sum game of Medicaid funding.

Oregon's Proposed Solution

Improving access to basic health care for low-income Oregonians was the positive counterpoint to reductions in access to more exotic care. Like most states, Oregon has a growing segment in their population of 2.7 million, who lack health insurance. As of 1987, over 400,000 Oregonians under the age of 65 have been without insurance, leaving one in six heads of households under the age of 65 uninsured. Employed workers and their dependents comprise sixty-five percent (260,000) of the uninsured, of which 110,000 or more are children. Eight to fifteen thousand uninsured people are unable to purchase health insurance because of pre-existing health condition.¹¹ Eligibility for the joint federal and state funded Medicaid program in Oregon has become more stringent since its inception in 1965 as Oregon, like many other states, has sought to limit increases in their contribution to the increasingly expensive health care bill. Currently, Oregon restricts Medicaid eligibility to those persons or households earning below 52 to 58% of the Federal Poverty Level, depending on household

¹¹ Shostak D. Briefing: the Oregon response to the medically uninsured. Bioethics Consultation Group, Inc., July 1989.

size. Estimates have been made that 130,000-140,000 state residents qualify for medical assistance, with 66,000 of those being persons under the age of 21 years.¹²

In the debate which followed the legislature's decision to divert funds for transplantation to expand the number of recipients of more basic care, attention was focused on the need to develop a more ethically and methodologically sound approach to compare the value of all medical services covered under Medicaid. In response, a statewide effort coordinated by the private, non-profit group Oregon Health Decision was begun to establish a public consensus, through an extensive series of town meetings in its 1988 meeting series, on principles by which health care resources should be distributed by government. The document that was produced from their efforts, "Quality of Life in Allocating Resources,"¹³ outlines in a set of fifteen principles the purpose of health services, and the rationale and method for setting priorities in health resource allocation. The Medical Research Foundation of Oregon, a progressive group of philanthropic, legislative and medical care leaders organized a process to prioritize Medicaid services to be informed and guided by the Oregon Health Decisions consensus results.¹⁴ The Berkeley-based Bioethics Consultation Group was commissioned to assist in establishing a priority list of services using small group meetings of health care providers charged with establishing a consensus on priorities.

¹² Id.

¹³"Quality of Life in Allocating Health Care Resources: principles adopted by the Citizens Health Care Parliament, September 23-24, 1988, Portland, Oregon." Oregon Health Decisions, December 1988.

¹⁴Golenski JD and Shostak DI. Prioritizing medical care resources: lessons from 1989. California Hospitals, March/April 1990: 15-17.

The priority-setting project invited community volunteers, including "senior physicians, nurses, social workers, and health and social service program administrators," to form focus groups "representing four segments of the Medicaid population: Women in their reproductive years (the OB/GYN group); Children from birth up to the age 18 (the Pediatric group); Adults from 18 to age 64 (the Adult group); and the elderly defined as persons over the age of 65 (the Geriatric group)."¹⁵ The groups were directed to determine a list of "necessary" care and then "to rank-order the elements of their list from the most important and necessary to least necessary." A single representative from each of the focus groups joined an executive group, which melded the four priority lists into one master list. The executive group included a legal services lawyer, an epidemiologist, and the Oregon Health Sciences University ethicist who also represented Oregon Health Decisions. The cost of each item was then calculated by an actuary.

The 1989 Oregon legislature was presented with the report on prioritizing prepared by the Bioethics Consultation Group, as well a report submitted by the Governor's Commission on Health Care which outlined a strategy to to extend Medicaid coverage to the 77,000 Oregonians that would be eligible if coverage included those citizens with family incomes below 100% of the Federal Poverty Level. A legislative strategy was developed and presented in Senate bill 27, which sought to expand access to a package of Medicaid benefits that was determined by prioritizing services.

¹⁵Golenski JD and Blum SR. The Oregon Medicaid priority-setting project. Bioethics Consultation Group, Inc., Berkeley, California; December 1988- March 1989.

In addition, two other bills were proposed to address the medically uninsured who are not eligible under Medicaid. As discussed below, Senate Bill 534 aimed at providing coverage for the medically uninsurable, while Senate Bill 935 was directed at mandating employers to provide health insurance to their employees.

Senate Bills 534 and 935

Senate Bill 534 dedicates \$1 million of state funds to establish a state insurance pool for the medically uninsured. The bill also contains a provision which allows additional funds for the pool to be assessed on insurers. Senate Bill 934 charges an Insurance Pool Governing board to provide a package of insurance benefits "substantially similar" to the one established by the prioritizing process under SB 27. The bill allows employers of less than 25 employees to purchase coverage under this package at a rate of \$40 per employee per month, with an employee contribution limited to either 25 % of cost or \$15 per month, whichever is the lesser. Employers will be required to offer insurance to their employees and dependants by January 1994 or begin making monthly contributions to the Insurance Pool Fund based on a percentage of their taxable payroll at a rate not to exceed 75% of the cost of the plan for employees and 50% of the cost for employee dependents. Tax credits would be available in the first five years of the program to encourage employers to provide coverage.

Senate Bill 27

SB 27 is the centerpiece legislation in the three-part strategy to improve access, as it provides the mechanism to establish the minimum set of benefits

for both Medicaid and employer-provided coverage, and limits the state's financial obligation to those covered under Medicaid. Under SB 27, federal waivers are being sought so that a newly established Health Services Commission will be authorized to establish benefits for Medicaid recipients in the state. If and when the federal waiver is approved, the Commission is required to provide a prioritized list of services to the Governor in July of each year, along with an actuarial report indicating the costs and appropriate rates at which to fund these recommendations. The Joint Legislative Committee on Health Care is charged to determine whether or not to recommend the determined priorities to the Legislature, which by statute must act. Benefits under SB 27 are to be offered to Oregonians at or below 100% of the Federal Poverty Level. The budget for funding the program is fixed to state revenue levels, and if revenues decline, the program is authorized to reduce benefits, but not eligibility. If all 77,000 newly eligible Oregonians were to enroll, the current available monthly fee to providers would be about \$72.50 per person per month.¹⁶ Current Health Maintenance Organization rates in Oregon are approximately \$90 per month per person.¹⁷

The process of prioritization in Oregon, as mandated by Senate Bill 27, was to be coordinated by a newly established Oregon Health Services Commission and to involve input from several sources. The eleven member Health Services Commission was required to compile "a list of health services ranked by priority, from the most important to the least important,

¹⁶ See Exhibit 1 in the appendix.

¹⁷ Shostak D. Briefing: The Oregon response to the medically uninsured. Bioethics Consultation Group, Inc. July 1989.

representing the comparative benefits of each service to the entire population to be served."¹⁸ A Social Values Subcommittee set up a series of statewide community meetings to satisfy the Senate Bill 27 mandate to "actively solicit public involvement in a community meeting process to build a consensus on the values to be used to guide health resource allocation decisions."¹⁹ A Health Outcomes Subcommittee undertook the task of obtaining information on the comparative benefits of various health treatments by and soliciting information from Oregon physicians on "the expected outcomes of condition-treatment pairs, as well as the probability of those outcomes occurring."²⁰ In addition, "selective literature searches would be made on those areas of practice for which there is known, viable research and for those treatments for which there is no Oregon-based information."²¹ Furthermore, the Mental Health Care and Chemical Dependency Subcommittee was charged to evaluate and report to the legislature whether it was reasonable to consider prioritizing the state's mental health care and chemical dependency services.

Oregon's Method

As conceived by the Oregon Health Services Commission, the process of prioritization is essentially one of ranking medical condition-treatment pairs by their cost-utility ratios. The net cost of treatments are determined by the difference between the cost of providing full treatment and the cost of providing "some level of service [that] would be given to ensure the

¹⁸ 65th Oregon Legislative Assembly, Senate Bill 27, June 13, 1989; p.3, lines 11-13.

¹⁹ *Id.*, p.3, lines 8-10.

²⁰ Oregon Health Services Commission, Preliminary Report, March 1, 1990; p.6.

²¹ *Id.*, p.6.

comfort of the patient".²² This level of palliative care is termed "proxy treatment." The utility provided for each condition-treatment pair is measured in life years gained with full treatment versus with proxy treatment. The value of these life years are adjusted according to the probability and duration of quality-reducing residual effects of a condition that may occur given full and proxy treatments. Thus a year of life confined in bed would be "quality-adjusted" to be worth less than an otherwise healthy year of life. The quality-adjustment factor for a given health state is to be based on the relative value that polled Oregonians have placed on that state of health. A demographically representative sample of Oregonians were polled to obtain their personal valuation of life as affected by a wide variety of health states. Finally, quality-adjusted life years are discounted in the equation to account for time preference, while the costs are adjusted for the rate of inflation and the medical consumer price index.²³

In addition, public input into prioritization was elicited through public meetings conducted in each of the state's counties. A series of forty-seven town meetings were conducted across the state by Oregon Health Decisions to form a community consensus on the values which should guide how health resources are allocated. The format consisted of an introductory presentation of the issues facing the health care for the poor in Oregon, followed by a facilitated open debate by the public. Attendance by the general public ranged from 3 to 120 people with an average of 20 people.²⁴

²² Id., p.10.

²³ See Exhibit 2 in the Appendix.

²⁴ Hasnain R and Garland M. Health care in common: Report of the Oregon Health Decisions community meetings process (Report to the Health Services Commission to

The composition of those attending did not represent the population demographically, with the poor, Medicaid recipients, and the medically uninsured being significantly underrepresented.²⁵ The recently published results of this effort presents the values generated by these discussions in terms of the frequency with which the value was brought up in the meeting. Thus the values of "prevention" and "quality of life" rated "very high" as they were mentioned in every meeting. In contrast, values such as "community compassion" in preserving the integrity of an individual and their family, "personal responsibility" for health, and "length of life" were rated as medium low in that they were mentioned as significant values for guiding resource allocation in less than one half of the community meetings.²⁶

While SB 27 mandates that the prioritization effort be guided by the results of these meetings, there is no method specifically proposed to do this. The priority list which has just recently been generated is based on the cost-utility method outlined above. Adjustments to this list may be made based on the "community values" which have been assessed, or by the public input provided during a series of public hearings which are to be held before the priority list is implemented.

Regardless of what changes will be made in the future, the proposition of operationalizing community values into the priority list format remains problematic. This paper will focus on how the proposed method of

identify public values for use in health services prioritization process) April 1990. Oregon Health Decisions, Portland, Oregon.

²⁵ See Exhibit 3 in the Appendix.

²⁶ See Exhibit 4 in the Appendix.

incorporating individual's values toward quality of life in cost-utility assessments has set the agenda for how the value of health care is to be decided. This method makes some definite assumptions about how health care can and should be valued, who should make these valuations, and how these values should be applied to resource allocation. In the following sections, I intend to examine critically these assumptions, as well as address some of the more general problems associated with establishing and implementing a policy which proposes to limit particular health care services. These issues question, in general, the role and responsibilities of government and the health care system in our society. Many of the issues that the Oregon proposal raises, however, are relevant to larger questions of how a society is to set a value on health care in the face of other competing demands for its resources, and how it is to establish and operationalize limits based on those values.

III. Valuing Health Care: Quantifying Benefits

Cost-utility analysis challenges society to define our expectations about what we as a society expect from the health care system, and confronts what its willing to sacrifice towards satisfying those expectations. Oregon's analysis of "utility," in its attempt to involve the public and directly incorporate societal value judgements about various health states, is rather unique in health policy formulation. This is due in large part to the general difficulty involved in the assessment of utility, its valuation, and its predictability. Oregon proposes the use of a cost-utility analysis method developed by Kaplan and Anderson²⁷, which calculates utility by estimating the probability of various health outcomes for condition-treatment pairs and attaching a value to those outcomes through a survey that asks the public to rate various "health situation[s] on a scale of 0 to 100, where 0 is death and 100 is good health."²⁸ Such a method is praiseworthy in its attempt to involve the health care consumer in the valuation process. It also orients the evaluation of health care around functional assessment by the patient, instead of clinical/physiological assessment by caregivers, which may be detached from the patient's experience of their illness. The validity of this tool is controversial and its implications for the way public opinion is used in forming health policy is troubling.

Health preference research began in the 1970's in an attempt to evaluate how people measure the value of health. The methods used for eliciting

²⁷ Kaplan RM and Anderson JP. A general health policy model: Update and applications. Health Services Research, June 1988. 23,2: 203-235.

²⁸ Oregon State University, Health Status Telephone Survey; Corvallis, Oregon, January 1990. See Exhibit 5 in the Appendix.

such valuations are many and vary as to how questions are asked, who is questioned, and the scale to which preferences are attached. Major problems associated with such calculations of utility include the scope of health states assessed, the construction of a scaling task, measurement of statistical reliability and validity, and the aggregation across interpersonal utilities.²⁹ The application of these measurements to public policy making is controversial. It raises questions about the appropriateness of using the highly theoretical method in making such important decision. More importantly, it opens to question how democratic values are to be incorporated into public policy? Indeed, the most prominent rationale for including direct public involvement in the process of prioritization is that health care maintains a special status in the public welfare. Issues of health impact an individual's well-being in ways that are so significant and so highly personal that they mandate personal input in decision making. And yet it is the personal nature of health care that renders generalization by majority decision making dissatisfying in its premise. The political discomfort involved in intervening in this personal realm by establishing limits on particular health services may explain in part the prevailing tendency to exclude more people from eligibility instead of reducing services from the eligible.

In matters of public policy that have budgetary impact, there is a need to value the impact of decisions. A monetary valuation is necessitated in cases when benefits must be weighed between programs. The currency of value in health care determines the quantity to be maximized. The traditional

²⁹ Mulley AG, Assessing patient's utilities: can the ends justify the means? *Medical Care* March 1989.27, 3 (Supplement).

reliance on dollars as the measure in health policy decisions has well-known biases, such as those favoring acute over preventive care. For intra-program evaluation, however, other measures can be sought. Health care programs can use as a variety of measurements to compare the value of various programs. When initiatives like prioritization propose to evaluate the entire spectrum of policy choices which fall under the auspices of health, from seat belt laws to the funding of hospice care, a common measure must be found. The search for and refinement of this measure challenges society to name what "health" is in terms that are universal and interconvertible between health care services and among individuals.

Quality-Adjusted Life Years

Oregon has chosen quality-adjusted life years (QALYs) as their currency of health, and the biases presented by this valuation are less well appreciated. Most of the development and criticism of QALYs has occurred in Great Britain, where it has been proposed for use in health care allocation decisions for the National Health Service. They have been championed because of their 'egalitarian' valuation of years, in that "each individual's health is counted equally,"³⁰ and for their sensitivity to the quality of life due to changes in health. Criticisms include that they are ageist, undemocratic, potentially sexist and racist, and generally incompatible with an ethical system of distribution of resources. I will discuss further the ethics and implications of using QALYs as a measure in health care allocation decisions in this section of the paper.

³⁰ Torrance GW. Measurement of health state utilities for economic appraisal. *Journal of Health Economics* 1986. 5: 1-30.

The concept of QALYs represents an attempt to quantify the results of health interventions in terms which are more sensitive to how people value outcomes than the traditional measurement of five-year survival rates. While survival rates have their place in the evaluation of interventions, they are becoming increasingly inadequate as the majority of medical therapies which are currently being developed are for chronic conditions that are not life-threatening. With the assumption that a year under certain conditions of health may be preferable over a year under other conditions, QALYs seek to describe the relative value of length versus quality of life. Described by one of its chief architects, Alan Williams, the QALY fulfills the role of "a simple, versatile measure of success which incorporates both life expectancy and quality of life, and which reflects the values and ethics of the community served."³¹ The universality of the QALY as a measure of human well-being makes it potentially very useful in social decision making for comparing health programs. Proponents of QALYs argue that cost-utility analysis, a special form of cost-effectiveness analysis using 'QALYs gained' as a common measure, would allow comparisons across a wide range of welfare programs.³² The scope of such analysis in the United States is so broad that it could potentially have Medicaid and Medicare reimbursement decisions competing with other programs which aim at improving quality of life, such as Head Start and mainstreaming efforts for the handicapped.³³

³¹ Williams A. The value of QALYs. *Health and Social Service Journal* 1985.

³² Torrance GW. Measurement of health state utilities for economic appraisal. *Journal of Health Economics* 1986. 5: 1-30.

³³ Mosteller F. Implications of measures of quality of life for policy development. *Journal of Chronic Disease* 1987. 6: 645-50.

While the idea that programs could be ranked according to their cost-per-QALY is endorsed by many, the desirability of such a policy should be examined. Loomes and McKenzie suggest three questions that must be answered before recommending cost-per-QALY as a basis for resource allocation:

- (1) Whether any of the existing methods for eliciting quality of life valuations are reliable and valid.
- (2) Whether individual valuations can be scaled and somehow aggregated to give measures which enable legitimate interpersonal comparisons to be made.
- (3) Whether indeed the values to be used in social decision making should be some aggregate of individuals' valuations.³⁴

The first question addresses the methodology of assessing health status valuation in populations, whether it accurately reflects human preferences about health care alternatives. The second and third questions aim at the appropriateness of applying these valuations in decision making. I will discuss below the methodological and ethical problems associated with both aspects of QALY use.

Measuring Health Status Preferences

The proposition inherent in the notion of the QALY is that individuals, when allowed to choose, will always select options which will maximize their QALYs. Thus some balance is proposed to exist between individuals' preferences between length of life and quality of life. The task of QALYs

³⁴ Loomes G and McKenzie L. The use of QALYs in health care decision making. *Social Science and Medicine* 1989. 28, 4: 299-308.

then is to ascertain the appropriate balance of preferences for longevity and quality of life. Although this trade-off seems intuitively to reflect human preferences, certain empirical and theoretical evidence suggests that human decision making is not fully captured by the QALY model.

First is evidence that questions the assumption of a constant proportional time trade-off between length of life and health status. This assumption states that individuals are willing to 'sacrifice' some constant proportion of the remaining years of life in order to achieve a given improvement in their health status, regardless of the absolute number of years that remain. Thus someone who regards 12 years of perfect health as equivalent to 15 years in their current health state is assumed to consider 4 years of excellent health as equivalent to 5 years in their current health state.³⁵ Some experimental evidence casts doubts on this assumption. McNeil *et al.* conducted a study which showed that individuals are only willing to trade life-years for an improvement in health status when the length of time to be spent with less than perfect health, a diminished speech volume in this case, exceeded an *absolute* value of five years.³⁶ In this way, trade-offs are complicated by conditional restrictions which undermine any simple proportional valuation. Other evidence shows that the values that individuals place on various health states differ significantly with the duration of those states.³⁷ In their discussion of how duration of health state affects preferences, Sutherland *et al.* suggest the concept of a

³⁵ *Id.* p.300.

³⁶ McNeil BJ, Weichselbaum R and Paulker SG. Speech and survival: trade-offs between quality and quantity of life in laryngeal cancer. *New England Journal of Medicine* 1981. 305: 982-87.

³⁷ Sackett DL and Torrance GW. The utility of different health states as perceived by the general public. *Journal of Chronic Disease* 1978. 31: 697-704.

'maximal endurable time' as the length of time beyond which individual preferences over alternative health scenarios changed relative to preferences involving shorter periods of time in the same health state.³⁸ Based on this limited, but unfavorable evidence, researchers and policy-makers should be cautious about the assumption that the balance between preference for length and quality of life can be expressed in simple algebraic terms.

Another issue confounding the constant proportional time assumption is that of time preference in consumption. The notion of time preference is that the timing of an event may influence the value that an individual places on the event. Time preference is commonly explained by the generic human preference for the present consumption of a commodity over the consumption of that same commodity at a future time. In cost-utility analysis, both the future cost and utility of a decision must be discounted. This discounting is done at a constant rate, which is based on both empirical models of human preferences and the rate of return for monetary investment in financial markets.

Loomes and McKenzie argue that 'consumption of life' cannot be considered in the same way as consumption of other goods. If an individual considered the value of life years today differently than those in the future, the constant proportional time trade-off assumption would be undermined:

³⁸ Sutherland HJ et al. Attitudes toward quality of survival: the concept of maximal endurable time. *Medical Decision Making* 1982, 2: 229-309.

For example, if a geometrically declining series of weights were attached to future periods, it is straightforward to show that for any given health state rated lower than excellent health, the proportion of Y [years in a given health state] that individuals would be willing to sacrifice to achieve excellent health will decrease as Y decreases.³⁹

The result is that the value attached to a year in a given health state is not fixed, but instead varies with the duration of that health state. Thus a constant proportional preference between quality and quantity cannot be made if the usual adjustment for time preference is calculated. In addition, the authors suggest that other factors may combine with 'pure' time preference to explain the more complex observed valuation of future health states. They suggest that the desirability of full health varies according to the part of individual's life cycle being considered. For example, a woman may value health during her childbearing years as more valuable than health in other periods in her life. There is some evidence that people do value health as being more important during certain life stages.⁴⁰ In particular, individuals have been shown to value health in certain later stages of life as being more valuable than in earlier ones. This point has additional significance in assignment of interpersonal utility among individuals of different ages, a point which I will discuss later in this paper.

A second assumption made in the use of QALYs is regarding individuals' attitudes toward risk. Many health care alternatives require the patient to assess and weigh risks and uncertainty in decision making.

³⁹ Loomes G and McKenzie L., p.300.

⁴⁰ Williams A. Economics and the rational use of technology. In *The Economics of Medical Technology* (Edited by Rutten FFH and Reiser SJ). Springer, Berlin 1988.

There is substantial evidence, both clinical and non-clinical, that attitudes toward risk and uncertainty have a significant effect on the valuation and choice of health care alternatives. Some methods for calculating utility attempt to account for differences in individual attitudes regarding risk and uncertainty, while other methods simply neglect its effect. In attempting to place a value on individual attitudes toward risk, methods commonly assume that a constant value can characterize an individual's general attitude toward risk-taking, independent of the duration and nature of the risk. And yet, individuals display a complex pattern of both risk-taking and risk-avoiding behavior that is not so easily characterized. The method used in the Oregon proposal implicitly assumes a risk neutrality, in that it does not even attempt to calculate attitudes toward risk and uncertainty. In the Oregon method, individuals are asked to value the certainty of a state of health without considerations of prognosis. Inasmuch as this method ignores the effects on the valuation of health states by variations in individual attitudes toward risk, it misses a major component in assessing individual preference.

The discussion above suggests that attempts to establish preference scales for health status may be more complicated than recognized by Oregon's methodology. The characterization of human preference and its translation into a mathematical form which could be applied in quality of life calculations is still in a highly theoretical stage. The perfection of the method is ongoing and may eventually succeed in closer approximating human preferences and values.

QALYs in Health Care Decision Making

Assuming that reliable and valid measures for quality of life valuations can be found, I would now like to address the second question posed above, regarding the comparison and aggregation of individual quality of life valuations among individuals. The notion behind the use of a population-based valuation of health services is that allocation decisions should reflect the distinct values of a society. Given the variability in preferences between individuals in that society, how are these variations to be aggregated and synthesized? While the previous section addressed the ability of QALYs to reflect individual health preferences, the discussion below will examine the appropriateness of using QALYs in social decision making. There are two sets of concerns regarding the use of QALYs in decision making. One is the set of issues surrounding equity and egalitarianism in their use. The other centers on the desirability of such a decision making apparatus in a democratic society that values highly the protection of individual liberty.

Equity is a central concern in the implementation of a QALY-based decision-making apparatus. As posed in the second question above, how are legitimate interpersonal comparisons of utility to be made? The most common method of scaling individual valuation for aggregation is to assign a value of 1 to describe a state of full health, and a value of 0 to describe death (the Oregon system uses values of 100 and 0, respectively). Valuations of other states of health are then standardized according to this scale. QALY pliers claim that this method assures equality in interpersonal comparisons:

The central basis for this method is that the difference in utility between being dead and being healthy is set equal across people. In this way the method is egalitarian within the health domain; that is each individual's health is counted equally.⁴¹

The decision to weigh all QALYs equally is considered by many supporters to be a guarantee that the method will ensure equity in allocation of resources among individuals. Thus, the fact that a sixty-year-old's QALY is equivalent to a six-year-old's QALY is offered as proof that "each individual's health is counted equally."

Such a claim of equity is disputable on several points. Some authors suggest that there may be reasons that QALYs should not be considered equivalent. As was mentioned above, some empirical evidence, for example, has shown that individuals may value health differently depending on their age. If valuation of QALYs is supposed to reflect individual preference for health, then it might be necessitated that QALYs be weighted by age. Loomes and McKenzie an "alternative 'egalitarian' principle" by which such age-based preference for health is accommodated. The principle has two components:

i) that an extra year of healthy life for one person in his/her n th year should be given the same weight as for any other person in his/her n th year; and (ii) that one individual's preference for a year of good health during his/her n th year over good health in his/her m th year should be given the same weight as as any other persons relative preference between m th and n th years.⁴²

⁴¹ Torrance GW. Measurement of health status utilities for economic appraisal. *Journal of Health Economics* 1986. 5:17.

⁴² Loomes G and McKenzie L. p.304.

In this scenario, the authors consider two individuals age 40 and 70, who are competing for funds that can produce only one extra year of healthy life. According to the above principles, if both individuals regard good health at 40 years as more valuable than good health at 70 years, then the resources should be spent on the 40 year old. The authors state that the principles they invoke are not less egalitarian than the equal valuation of QALY supported by most. The question raised by this suggestion is that if there are recognized and agreed upon differences in valuations, how are unequal states to be weighted? In addition to age-based differences preferences, are there may other such preferences that would complicate interpersonal comparisons of utility? This presents a major theoretical challenge to the development of a more sensitive system for accommodating values which arise at a societal level.

Another issue which complicates these attempts, is the fact that the values established by aggregated preferences may differ according to who is questioned. Oregon made the decision that preferences should be based on a sample of citizens who represent the general population, based on a notion that democratic participation would ensure that community-based values would be honored. The issue is complicated by the contention that the general population may not be the most qualified group to make judgements about the quality of life under various health states. One might argue, for instance, that health professionals, having worked with a broad range of patients with varying degrees of disability may be most qualified to assess the differences in the quality of life. This was indeed the initial approach taken by the health leadership in Oregon, as described above in the "Oregon Priority-Setting Project." One argument against this approach

point to the difference between the physician's assessment of disease and patient's experience of illness. In addition, some claim that it is the provider-oriented priorities in health care which have brought on much of the expansion of technology and cost that has forced the need to reorient health care resources.

One of the central problems in assessing health preferences is that of imagination. Is the collective imagination of society vivid enough to fairly assess the value of life, for example, in a wheelchair or on kidney dialysis, or should the judgments of patients who have suffered with a particular health state claim to have a more qualified opinion in the assessment of preference? Allowing only those who have experienced a given health state to quantify their preference, may be more satisfying to concerns over an individual's competence to make an informed decision, but it also may tend to reinforce the current distribution of resources. Alternately, the general population may be questioned as was the case in Oregon. Polling an otherwise unprepared individual about how they would quantify the value of life under a wide variety of conditions seems dissatisfying as well. Currently, it is not known how providers, sufferers and the general population differ specifically in their attitudes toward health status preferences. The point is of significant concern, however, if suffering is to be truly minimized by changes in resource allocation.

Even if we assume that the ideal set of preferences should be one that represents the general population, as was the case in the methodology adopted by the Oregon Health Services Commission, then a representative sample of the population should be polled. The selection of a sample which

is truly representative presents its own methodological problems. There are some members of society who would be affected by allocation decisions, but could never be included in such a survey. These include children, the mentally ill and the developmentally disabled, among others. Because of their silence, their preferences would not be taken into account. Furthermore, if a full accounting of utility is to be made, the utility of all those who are affected by an individual's illness should be taken into account. The impact of resource allocation decisions on the utility of caregivers specifically needs to be addressed. Elimination of funding for such services as hospice care for the terminally ill made indeed have more of an impact on family members who may otherwise have to care for the patient, than on the patient herself.

IV. Equity and Justice in Priority-Setting

Oregon's priority-setting system has difficulty in accommodating values which lie outside of the realm of those generated by quality-adjusted life years. It has been argued that what QALY-based cost-utility analysis values is quality-adjusted life years, and not people.⁴³ There are other concerns and values that society holds, which may call for modification of the proposed priority-setting method. These center around issues of equity and justice that are not addressed in this decision making model.

The Lack of a Defined Minimum Level of Care

In discussions of society's obligation to provide health care to its people, it is generally held that government should provide some decent minimum level of health care for the nation's poor. What services should be included in this minimum level is debatable. Egalitarians such as Daniels have argued that such an obligation arises from principles of justice, which require a just society to provide its citizens with a "fair equality of opportunity."⁴⁴ Access to health care is necessary to assure that each member of society may pursue their potential in life, unhindered by the lottery of ill health. In contrast, libertarians have argued that any obligation to provide health care for the poor arises from principles of beneficence rather than justice. The claim for beneficence contrasts with that for social justice, in the egalitarian argument, in its relative strength, and allows for a lower standard of care for the poor. The egalitarian view as expressed by Daniels also permits limits to be placed on what kind of

⁴³ Harris J. QALYfying the value of life. *Journal of Medical Ethics*: 1987, 13: 117-123.

⁴⁴ Daniels N, *Just health care*, Cambridge University Press, New York, 1985.

care an "opportunity" based claim would require. The practical formulation of what such a minimum would consist has not been attempted, part because of its theoretical and practical complexity. Fleck points to concerns over questions of financing, cost containment, technology and self-inflicted health problems as among the factors which complicate the establishment of a comprehensive conception of justice in health care.⁴⁵

As formulated in the Oregon program, the basic minimum level of health care to be provided to the poor would not be determined by need, but rather by the available revenues that the state determines is within its budget for health services. Because of this, no guaranteed level of care or floor of benefits is mandated for recipients. As funds are reduced, services from the bottom of the priority list would be eliminated. The potential exists that revenues could not provide a standard health care package that adequately addresses the basic needs of recipients. Estimations of the funds available per patient under the fully expanded Medicaid eligibility⁴⁶ are approximately 20% short of the estimated average cost per person for HMO enrollment⁴⁷ in Oregon. This fact suggests that substantial cuts in services below what is currently provided to HMO enrollees will be required to expand enrollment. Without language in SB 27 requiring a minimum level of services to be established, there is no limit to the services which may be cut as enrollees and costs increase or state revenues decline.

⁴⁵ Fleck LM, Just health care (II): Is equality too much?. *Theoretical Medicine* 10: 301-310, 1989.

⁴⁶ See Exhibit 1 in Appendix for the Oregon Health Commission's estimates of available funds per enrollee.

⁴⁷ Estimated cost from Shostak D. Briefing: The Oregon response to the medically uninsured. Bioethics Consultation Group, Inc. July 1989.

Distributional Concerns

Any decision making method that relies on the maximization of life-years will tend to favor interventions which provide benefits that improve life for those with longer life expectancies. The age preference inherent in the method is controversial. There is a substantial body of literature which debates the appropriateness of using age as a criterion for the allocation of medical resources.⁴⁸ While some authors tout therapies such as hip replacement surgery for elderly patients as performing very well in cost-effectiveness analysis, there are many therapies which will be handicapped because the average age of those treated is higher than the median age of the general population. By Oregon's method of cost-utility analysis, costs and benefits condition-treatment pairs are calculated for the average age of patients affected by a condition. Even if society agrees that years of benefit provided by a treatment should be important in allocation decisions, patients younger than the average of affected patients could potentially be denied access to treatments that would prove 'cost-effective' if their actual age was considered. This fact suggests that the method should include a more thorough analysis of how age and other patient characteristics influence prognosis.

Another concern is the fact that cost-per-QALY rankings only consider maximizing the number of QALYs for a given input, without regard for the distribution of those QALYs. Thus, allocating resources such that

⁴⁸ For a review of this debate see: Kilner JF. Age as a basis for allocation lifesaving medical resources: An ethical analysis. *Journal of Health Politics, Policy and Law* Fall 1988. 13,3: 405-423.

seven people receive one additional QALY is equivalent to an allocation that provides one person with seven additional QALYs on a strict cost-per-QALY basis. Equity in distribution of health care is not served this model. Nevertheless, some notion of equity appears to be important in the distribution of health and health care among other things in society. Indeed, the value placed on equity might be incorporated into this decision making model if an adequate definition(s) of equity could be agreed upon, measured and operationalized. This is at present a highly theoretical proposition. Furthermore, individual preference for access to certain treatments may not be compatible with a QALY maximizing principle. For example, individuals may prefer a less effective therapy if it means that they will be more likely to have access to that therapy. Suppose that there are two treatments, A and B, for a condition such that A produces 3 QALYs per person treated and B produces only 1 QALY per person treated. If A costs twice as much per treatment as B, then a cost-per-QALY calculation favors A. If the lower cost of B allows twice as many treatments to be provided, however, it is possible that the healthy population will prefer the allocation which increases their chance of receiving a smaller benefit.⁴⁹ Alternately, individual attitudes toward risk and uncertainty may show a preference for certain therapies which are very costly, but highly effective, such as trauma care systems for rural communities or organ transplantation. Although the probability of using these services are small for an individual, risk seeking individuals may feel that such a gamble is justified.

⁴⁹ Loomes G and McKenzie L. p.305.

It has been suggested that the value of health care extends beyond simply the production of life years. Mooney suggests that in addition to the utility that an individual receives from health interventions, there is another benefit that might be considered in terms of a "procedural utility," which may extend beyond a more selfish, outcome-oriented definition of utility.⁵⁰ Such utility is gained in the appreciation of process, rather than simply outcome. Procedural utility may be gained in such things as seeing equity in distribution of health services, as well as other process-oriented measures. One might consider, for example, the utility of being assured that one's children or one's neighbor can be seen by a physician when they are ill. Health care indeed has value beyond that which is measured merely by outcomes. For example, education and advice from health providers have an great impact on well-being. Much of the suffering in illness is due to uncertainty surrounding its cause and prognosis, which can be remedied with information alone. Such benefits, however, are poorly documented in health status assessment.

Justice and Systematic Discrimination

Decisions to limit access to health care have a significant impact on the welfare of citizens. The rationale for these decisions must be defensible, not only on the basis of the resultant outcomes that they produce, but also on the basis that they respect certain procedural rules that we value as a society. Allocation of resources on a principle of maximizing value on a cost-per-QALY basis potentially threatens to break some of those rules.

⁵⁰ Mooney G. QALY's: are they enough? A health economist's perspective. *Journal of Medical Ethics*, 1989, 15, 148-152.

The discussion below raises some potential challenges to societal values that the results of this allocation tool may bring.

Cost-per-QALY calculations are based on criteria which discriminate the value of therapies by prognosis. The age-based discrimination implicit in any decision making scheme which seeks to maximize life years produced per intervention was discussed above. There are other ways in which groups of our population could be systematically discriminated against on the basis of prognosis. For example, if it was found that, for physiological reasons, women or Asians or gay men did not benefit as much from a given therapy as the general population did, then there might be reasons on a cost-per-QALY basis to deny access to the therapy. Our society is one that values the protection of equal rights very highly and spends a great deal of resources in our judicial system to guarantee that these rights are respected. And yet this method of cost-utility analysis is indifferent to these rights. As this method becomes more refined in evaluating costs for treatments by age group, sex, geographic location and other demographic information, the potential for discrimination on a variety of qualifications will expand.

Another value our society holds, and which is protected by the state, is the protection of life. While the right to this protection faces a complex legal challenge by the effort to enact the prioritization of Medicaid, it is clear that the method itself does not guarantee the priority of life-saving therapies over those which simply improve the quality of life. For example, it has been shown that by cost-effectiveness analysis, that hip replacement surgery is a better value than renal dialysis. Choosing to fund

hip replacements over dialysis, however, would mean choosing to improve the quality of life over saving life. Clearly, life-saving therapies must have priority in certain circumstances, although the limits to this priority would be difficult to establish considering that the issue of quality of life itself was born from concerns that some states of health were worse than death.

Lastly, efforts to limit services may infringe on the value we place on an individual's autonomy. The implementation of coverage limitations and restrictions on treatment options imposes valuations of life with which individual patients might not concur. Unlike the personal nature of patient-physician discussion which allows for compromise between medical need and personal values to be met, dictated benefits undermine a sense of autonomy and power in decision making about the most significant decisions in life. Furthermore, the wide variability in preferences among individuals cannot be accommodated by such a system. The relative importance, for example, of a one-month remission for an individual who desires to set his life's affairs in order before his death, is not taken into consideration in a decision making apparatus which imposes an average community value for quality of life on individual preference. This problem of accommodating individual preference raises the larger issue of the appropriateness of even attempting to average the wide range of human preference into some standard value.

V. Outcomes Measurements: The Limits of Effectiveness Data

In calculating the value of health care in our society, there is an additional factor to consider beyond individual health preference, namely the effectiveness of the health care which is being purchased. Although the method of obtaining and applying this information is less controversial than that of utility assessment, thorough technology assessment may ultimately have more of an impact on the ordering of a priority list than utility calculations. The current scarcity of scientifically rigorous clinical testing of contemporary medical and surgical practices precludes any systematic application of this information into cost-benefit calculations. The Office of Technology Assessment has estimated that randomized clinical trials have been conducted for only 10 to 20 percent of current medical practices.⁵¹ The Office of Health Technology Assessment (OHTA), which reports to the Health Care Financing Administration regarding coverage for new technologies, has had difficulty in the past in making its recommendations because of the lack of rigorous scientific findings. Of the twenty-six assessments that the OHTA conducted in 1982, only two were based on randomized clinical trials.⁵²

Funding and coordination for technology assessment is piecemeal and insufficient. The only coherent, coordinated system for medical technology assessment is the premarket approval process for drugs and medical devices conducted by the Food and Drug Administration. Even

⁵¹ Office of Technology Assessment, U.S. Congress. *The impact of randomized clinical trials on health policy and medical practice 1983*. U.S. Government Printing Office, Washington, D.C.

⁵² *Id.*

this system only requires premarketing reporting for the safety and efficacy of drugs and devices, with no requirements of comparative studies of medical products, and only voluntary requirements for reporting of postmarketing adverse reactions. The assessment of most medical and surgical procedures, however, is performed within a loose network of relationships among public and private third-party payers, medical associations, private physicians, and the biomedical research community, who determine whether procedures meet the subjective criteria of "standard and accepted practice."⁵³ In addition, ad hoc expert consensus committees may be formed to establish effectiveness of therapies, as well as guidelines for their use, for procedures which have incomplete scientific data in their support. Where assessments require groups judgements, methods may be used which are methodologically unsound, and decision rationale and literature sources may go undocumented. Furthermore, consensus panels on the appropriateness of medical interventions appear to be biased according to the composition of their panel members.⁵⁴

The Oregon Health Services Commission's Health Outcomes Subcommittee appears to have encountered the problem of the adequacy of the medical literature in their search for outcome statistics. In their initial literature review, they recognized that this approach was "unwieldy and counterproductive because of the shelf-life of the data and questionable research methods."⁵⁵ The method that they opted for was essentially a

⁵³ See Institute of Medicine (U.S.). Division of Health Science Policy. *Assessing medical technologies* 1985. National Academy Press, Washington, D.C.

⁵⁴ See Brook RH, Kosecoff JB, Park RE, Chassin MR, Winslow CM and Hampton JR. Diagnosis and treatment of coronary disease: comparison of doctors attitudes in the USA and UK. *Lancet* 1988; April 2:750-753.

⁵⁵ Oregon Health Services Commission. Preliminary Report. March 1, 1990; p.6.

consensus model which asked "conventional and non-conventional providers" to identify "potential outcomes of condition-treatment pairs as seen in the Oregon experience."⁵⁶ The subcommittee developed a data collection form⁵⁷ which asked for the expected outcomes of condition-treatment pairs as well as the probability of those outcomes occurring, for both patients receiving full treatment and those receiving palliative or 'proxy' care. The conditions were segregated by provider speciality, and providers and professional societies were then identified to participate in providing outcomes data. Such a methodology is seriously flawed for many reasons, of which I will mention a few. First, respondents were asked to base their answers on their experience of outcomes with treatment is a subjective exercise at best. Second, judgements regarding the likely outcomes seen in those patients who do not receive treatment would be made from an even more limited base of experience. Third, it is unclear how these probabilities, once generated, would be transformed into a true consensus beyond a simple arithmetic averaging of opinions. In summary, this method is clearly no substitute for rigorous scientific evidence.

This vacuum of reliable data is a problem of great proportions. A nationally coordinated, methodologically standardized, well-funded effort to assess current medical practice, like the one proposed by the Institute of Medicine, would require years to institute and decades to complete. Thus any attempt to evaluate the benefits of health care based on considerations of effectiveness will be undermined by serious gap in information. The gravity of health resource allocation decisions presents a dilemma for

⁵⁶ Id. p.6.

⁵⁷ See Exhibit 6 in the Appendix.

decision-makers, who must face this limitation. On the one hand, since decisions about how health care resources are spent have such a significant impact on the lives of individual citizens, that accurate information is necessary to justify decisions. On the other hand, the pressing nature of allocation problems demand that some attempt should be made to make informed decisions despite methodological imperfections. One workable compromise that states like Oregon might undertake would entail a more modest effort to require new procedures to be evaluated for their comparative effectiveness with existing procedures before making coverage decisions.

VI. Problems in Implementing Prioritization

Prioritization has a pretense of objectivity that is undeserved. I have previously considered the biases inherent in the methodology. As great of a concern should be directed at how the results are implemented. While the calculation of cost-per-QALY helps to make explicit the trade-offs of health resource allocation decisions, it does not determine the task to which the method is to be placed. It is a political process between politicians, health care providers, and the public which will determine how the method is implemented. There several concerns about how the implementation of these results might affect the fairness and success of resource allocation under priority-setting.

The first is in the operational process of "bundling" services. The list of services as it is proposed to be generated would consist of treatments arranged according to cost-utility ratios. There are several ways in which therapies with high cost-utility ratios could be curtailed. The less 'desirable' therapies could be singled out and cut from a master list, as was "soft tissue transplantation" in the initial priority list created by the Bioethics Consultation Group.⁵⁸ Alternately, less desirable therapies could be bundled, as in the case of "fertility counseling" in the same list. Bundling may also be used ultimately to group patients by characteristics, such as age, sex and geographical location, which might affect the cost or

⁵⁸ Bioethics Consultation Group, Oregon's medicaid priority setting project, 1988.

prognosis of providing services. Bundling could be attempted along these criteria to include or exclude coverage for certain populations or treatment.

Bundling may be required at some level for several reasons. Practical organizational requirements of providers and beneficiaries might dictate the need for a service-specific, rather than a therapy-specific, list of coverage. Funding requirements of providers to maintain specialty services or clinics may require that therapies be bundled to assure sufficient funding. A service-based list may be desired for simplicity and clarity of coverage under Medicaid. In addition, the dictates of medical logic might demand that coverage for certain therapies not be singled out. Though this bundling may have its own logic, it also has an effect of hiding therapies with high cost-utility ratios by averaging out these ratios by service. This could be used as a powerful political tool to manipulate the 'desirability' of particular therapies. In this way, bone marrow transplantation might be combined with the less expensive chemotherapies for leukemia under a "leukemia treatment" category. For these reasons, bundling decisions deserve careful scrutiny.

The second concern is that over the responsiveness of a prioritization system to changes over time. The recalculation of cost and treatment data presents a costly and sluggish bureaucratic undertaking, while changes in information about diseases and treatment modalities tend to evolve rapidly. The need to adopt new information into use is often pressing. Consider the rapid emergence of recent therapies in the AIDS crisis, such as aerosolized pentamidine used for the prevention of pneumocystis carinii pneumonia.

Data on costs, utility, and outcome are likely to be incomplete and subject to significant variability over time.

In addition to the issue of the responsiveness of priority-setting to emergent needs, lies the more general effect that it would have on the adoption of new technology. Changes in technology will produce new therapies, which will have a generally less proven records of effectiveness. The result may be similar to the situation seen in the United Kingdom, where new technologies tend not to be adopted until their cost-effectiveness is well established. This may not be tolerated as well in the United States, where access to new technology is expected by patients. While it may less of a problem at first, the requirements of cost-utility analysis may eventually lead to the institutionalization of a second tier of technology for those patients covered under Medicaid. While a second tier of care system of care for the poor exists today, the lower level of services available to the uninsured is largely rationed by site. Thus county hospitals provide a level of care that is consistent, though lower than that available to privately insured patients, between all the patients it serves. When priority-based coverage under Medicaid establishes two tiers of care that must be provided in the same private hospitals, a difficult dichotomy will arise for providers. As new technologies supplant older ones for privately insured patients, the older Medicaid-approved technologies may become incompatible on a technical level. More importantly, the dual standard of care may prove morally intolerable for providers and patients alike.

Public reaction after implementation may question the results of the priority-setting. The general public may demand greater input in the

prioritization effort beyond random sample polling and public hearings. The gap between the community value-based principles, established by Oregon Health Decisions, and the final formulation of the priority list will very likely be challenged. Issues of equity will arise, as they did in 1988 over organ transplantation, as the public faces how limiting care actually impacts individuals. The force of public pressure, as well as that provided by special interest groups, on the legislature may be significant. As the media and special interest groups educate the public about the details of limiting care and introduce them to the lives of those who suffer from the range of human disability, there may arise a call to reassess the public's attitudes toward disability. To the extent that efforts at public education expand the public imagination of what various disabilities mean to one's quality of life, societal attitudes may indeed be affected. In addition, more focused pressure to make exceptions to a formula-derived priority list may succeed (e.g., consider the successful efforts to provide coverage for dialysis under Medicare in 1971). Safety valve mechanisms (e.g., media-initiated charity care) will likely be sought to provide unreimbursed services, which will tend to undermine the system's equity.

Lastly, although the current attitude of providers toward priority-setting is favorable (chiefly due to the provision to expand the number of indigent covered under Medicaid), their attitude may be soured as provider autonomy and income are infringed upon after implementation. Physicians will face the burden of an increasing need for patient advocacy in attempts to secure needed care, as they did with the introduction of DRG's under Medicare. The income of providers using high cost hospital-based, procedures would be most affected. Other factors would affect the

provider cooperation that would be necessary for prioritization to work. The threat of malpractice suits against providers for denying services would be real, despite the provision in Senate Bill 27 which would prohibit such action. Many more providers may choose not to serve the Medicaid population, until a sufficient amount of case law has been established to secure the legality of the provision. Finally, although providers would be convinced that they were containing costs by denying care in a "closed" system (i.e., money saved in denying care is being used to benefit others), providers would still bear what Aaron and Schwartz call "the psychologically unsupportable burden of denying care because it is too expensive".⁵⁹

⁵⁹ Aaron HJ and Schwartz WB. The painful prescription: Rationing hospital care, The Brookings Institution, Washington, D.C., 1984, p.128.

VII. Conclusion

This paper has considered some of the assumptions made in the prioritization effort in Oregon and their implications for the allocation of health care resources in the state. The method used to produce the priority list is flawed in its ability to account for all that society values in health care, as well as in the accuracy with which it determines the effectiveness of the health care that currently is provided. And yet, these two weaknesses exist primarily because they have not been stressed in the traditional decision making apparatus. The methodology for assessing preference for health status is embryonic in its development. The systematic evaluation of medical and surgical therapies, similarly, has not been undertaken due to a perceived lack of necessity. Refinement in both these areas is possible with the proper financial and technical support, and could greatly improve the accuracy of the method. Whether such an experimental method, however, should be tested in these crucial circumstances remains a central question. Some would argue that we should not look so closely at the quality of the evidence in support of the relative value of different health interventions, but rather we should look at the breadth of such evidence. This attitude overlooks the fact that, by this priority setting method, a line must be drawn that distinguishes valuable care from even more valuable care. The accuracy with which we draw this line will have great impact on individuals' lives. Accordingly, the method used to construct a priority list must be scientifically justifiable. Furthermore, since the method could have as great an impact on the population's welfare as the introduction of any new drug, it deserves to be rigorously tested before being implemented.

A massive trial of the method on the most vulnerable members of our society is not appropriate.

For policy makers, the idea of having a priority list is attractive, as it seems to obviate the need to make difficult ethical choices in coverage decisions. The priority list appears to have already made these choices for legislators. The method does not automatically decide, however, the levels at which to fund Medicaid services. It merely makes this choice explicit in its attempt to maximize benefits, or minimize suffering, in the allocation of scarce resources. Steps toward making resource allocation decisions a more explicit process are certainly an improvement over the current politicized and arguably arbitrary process under which organ transplantation funding was curtailed. The criteria for such decisions should be made as explicit in their method and implications as possible, so that decision makers can be held accountable for their choices. Public scrutiny should be two-fold. Firstly, the decision making criteria should be examined critically to see if they are reasonable and consistent with public values. This paper has attempted to begin this first critique. To date, however, neither the academic community nor the general public have commented on the decision making method. Secondly, the impact of these decisions should be examined to consider how congruent they are with public values and desires. This process has hopefully begun with the recent release in May 1990 of the initial priority list for Medicaid. Furthermore, public criticism may ultimately center not on the method of prioritization, but rather on the premise of the established budgetary limits. Public examination of the priority-setting process may result in a mandate to increase the state's contribution to the Medicaid program.

The implementation of prioritization of health care in Oregon faces serious obstacles. While objections to the system may be made on theoretical, ethical, and practical grounds, the most serious obstacle to its implementation, however, is political. The proposal must receive a waiver from the federal government, which is certain to be delayed due to election year politics. In addition, it will face difficult opposition to its implementation in Oregon as potential supporters will be hesitant to face up to the rhetoric of "rationing." Public support for the priority-setting approach will likely be determined by the contents of the coverage which the approach produces, as well as by the palatability of using a "rationing" procedure in health care decision making.

Since the provision of societally acceptable level of coverage under Medicaid will play a significant role in the success of the prioritization process, we should consider how coverage might look in the future under this plan. A major weakness of the Oregon plan is the way in which it addresses cost containment. The plan relies heavily on a managed care system to contain expenditures. This system has a proven limit to amount of savings it can provide alone, and does not address cost increases due to general medical inflation. Oregon's answer to increasing costs due to the introduction of costly new technology and medical inflation is to simply stop paying for those treatments which perform the worst by cost-utility analysis, such that the state's Medicaid budget is met. There is little incentive for providers to contain costs for the treatments which are covered under Medicaid, except for those treatments which are near the bottom of the approved priority list. In addition, because the scope of the

Oregon's Medicaid program has a limited monetary impact on the private providers of health care in Oregon, and even less of a fiscal impact on national producers of health care technologies, there is essentially no incentive to improve the cost-utility ratios of medical and surgical treatments. For the priority-setting method to succeed at encouraging efficiency in cost-utility terms, it would have to be implemented on a wider scale. As other states and private insurers are watching how the Oregon system fairs, success in Oregon may indeed bring a more widespread implementation.

The more likely short-term result for Oregonians, however, will be the continual reduction in the list of services covered by Medicaid as the costs for higher priority services rise. While reductions at the margins of the list will seem tolerable at first, gradually more significant services will be cut. Ultimately, comparing the value of vital services such as long-term care and hip replacement surgery by cost-utility analysis might seem inappropriate. Regardless of how such coverage decisions are resolved, prioritization will force the issue of how much society is willing to spend on providing health care for the poor. Prioritization will challenge government to justify not only its financial priorities in health care spending, but also the limits of its moral obligation to the poor.

Prioritization of health care services in Oregon represents an attempt to make the distribution of health care to the poor more equitable by reducing the number of benefits and increasing the number of beneficiaries. It offers hope that this distribution can be more rational and humane than the current system of denying health care coverage to large segments of our population.

Given the potential power of this method and the possibility of its widespread use, I have attempted in this paper to explore its weaknesses and pitfalls, not so much to condemn the effort, but rather to explicate its assumptions and implications. It is only through discussion and refinement of the method that prioritization can succeed in its claim of being a more ethical way to distribute our society's resources.

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Appendix

Exhibit 1

... funded at the level
... included in this ...

SHOWS FISCAL IMPACT OF SB 27 BY FEDERAL POVERTY LEVEL
4-3-89
Leslie H. filename = SB2792

EXISTING REVENUE

ZFPL	No. of Individuals	Monthly Cap Rate	Additional Individuals
58	160,854	\$95.76	
75	195,664	\$78.72	34,810
85	216,140	\$71.26	55,286
95	236,616	\$65.10	75,762
100	246,854	\$62.40	86,000

WHAT ADDITIONAL GF WILL PURCHASE

Capitation Rate	ZFPL				
	100	95	85	75	58
\$95	\$35,700,000	\$31,400,000	\$22,800,000	\$14,100,000	\$0
\$90	\$30,200,000	\$26,100,000	\$18,000,000	\$9,800,000	
\$85	\$24,700,000	\$20,900,000	\$13,200,000	\$5,400,000	
\$80	\$19,300,000	\$15,600,000	\$8,400,000	\$1,100,000	
\$75	\$13,800,000	\$10,400,000	\$3,600,000	\$0	
\$70	\$8,300,000	\$5,100,000	\$0		
\$65	\$2,900,000	\$0			
\$62	\$0				

Assumptions

Only program costs are shown. Administrative and contractor costs are not shown.
PLM and Medically Needy are included in the 58% group.

Federal Funds Match Rate is .6304 for Fy 1991
Total Fund available = \$184,834,498
General Fund available = \$68,314,830
GF as % of Total Funds = 0.3696
A 1% change in FPL = 2,048

Medicaid Programs for Aged, Blind and Disabled are funded at the level currently recommended in the Governor's Budget and are not included in this prioritization process.

Exhibit 2

$$\frac{1}{2} \left(\frac{1}{2} + \frac{1}{2} \right) = \frac{1}{2}$$

best ratio for
 The recipient
 will be used
 health services
 which the treatment
 with the n^{th} condition
 the patient's history

that the i^{th} outcome will
 occur.

variable denoting the presence
 health limitation (HSL), for a patient
 an i^{th} outcome with treatment
 by Oregonian's to the j^{th} health
 not ranging from zero significant

that the i^{th} outcome will occur
 treatment.

variable denoting the presence
 relation or chief event
 of treatment.

not during the k^{th} year
 ing all medication
 of the primary
 treatment for
 1. This may be
 cost of po

in literature

The information collected at the Commission's hearing and at Oregon Health Decisions' community meetings will be used as an "influence" factor for the following benefit/cost formula. These factors as well as the formula will be employed by the Commission in building a priority list of health services. The formula assumes that the proxy treatment is a substitute treatment of a less definitive nature. It may, however, have a higher benefit/cost ratio than the treatment currently being ranked.

$$B_n = \sum_{k=1}^y \frac{\sum_{i=1}^5 \left[(P_{i1} * (1 + \sum_{j=1}^{30} d_{ij1} w_j)) - (P_{i2} * (1 + \sum_{j=1}^{30} d_{ij2} w_j)) \right]}{(C_{k1} - C_{k2}) / (1 + R - MI)^k}$$

B_n = the benefit/cost ratio for the n^{th} condition/treatment pair to be ranked. The reciprocal of this value, termed the net benefit value, will be used in determining the actual rankings of health services from highest(-∞) to lowest(+∞).

Y_n = the years for which the treatment can be expected to benefit the patient with the n^{th} condition. This may be the remainder of the patient's lifetime or some shorter amount of time.

P_{i1} = the probability that the i^{th} outcome will occur five years hence with treatment.

d_{ij1} = an indicator variable denoting the presence (=1) or absence (=0) of the j^{th} health limitation (MOB, PAC or SAC) or chief complaint for the i^{th} outcome with treatment.

w_j = the weight given by Oregonians to the j^{th} health limitation or chief complaint ranging from 0=no significant effect to -1=death.

P_{i2} = the probability that the i^{th} outcome will occur five years hence with proxy treatment.

d_{ij2} = an indicator variable denoting the presence or absence of the j^{th} health limitation or chief complaint for the i^{th} outcome with proxy treatment.

C_{k1} = cost with treatment during the k^{th} year after onset of diagnosis, including all medications and ancillary services as well as the cost of the primary procedure.

C_{k2} = the cost with proxy treatment during the k^{th} year after onset of diagnosis. This may be the cost of a substituted treatment or the cost of no treatment whatsoever, which is assumed to be zero.

D = discount of future life-years

R = rate of inflation

MI = Medical Consumer Price Index indicating the rate at which medical expenditures are expected to increase.

Exhibit 3

STATE OF OREGON

... from Oregon...
... I have a...
... like to speak...
... she is at...
... person be...
...

... CONTINUE WITH...
... at Corvallis...
... about how people feel...
... the quality of their...
... Oregon's Health...
... programs for the...
... us is strictly...
... as a whole...
... at the interview...
... question that you...
... the next question...
... we would be happy...
... and he will answer...

... about how health...
... life, we would...

... describe several health...
... how you feel about...
... situation describes...
... feel it is as bad...
... is about halfway...
... You can use any...
... 75, 89, 100, and...
... 0 and 100.

... would assume you...
... Also, you...
... way?

... health situation...
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... and...
... the...
...

REP:

Phone No. _____

PAGE:

Area No. _____

January 1990

OREGON STATE UNIVERSITY

Final

"Hello, I'm _____. I'm calling from Oregon State University at Corvallis. First, I need to be sure I have dialed the right number. Is this (READ NUMBER)? "We would like to speak to the adult who has had the most recent birthday if he or she is at home now." (IF R IS NOT AT HOME ASK): "When would that person be home? (RECORD BELOW AND CALL BACK.)

(WHEN YOU HAVE CORRECT RESPONDENT, CONTINUE WITH): "As I said, I'm calling for Oregon State University at Corvallis. Our interview contains several interesting topics about how people feel about their health and how their health affects the quality of their lives. The information is important for it will help Oregon's Health Services Commission plan future health support programs for the state's citizens. All information that you give us is strictly confidential and the results are summarized for the state as a whole, not for any one person. Also, I want to assure you that the interview is voluntary, and if we should come to any question that you don't want to answer, just say so and we'll go on to the next question. If you have any questions after we have finished, we would be happy to have you call the study director at 737-3773 and he will answer them for you.

"Because people have different ideas about how health problems affect their happiness or satisfaction with life, we would like to ask how you feel.

"In the next few minutes, we will describe several health situations. We would like you to tell us how you feel about each one by giving it a score. If you feel the situation describes good health, give it a score of 100. If you feel it is as bad as death, give it a score of 0. If the situation is about halfway between death and good health, give it a score of 50. You can use any numbers from 0 to 100, such as 0, 7, 18, 39, 50, 63, 78, 89, 100, and so forth. Remember, you can use any number between 0 and 100.

"For each health situation, you should assume you would have no other problems than the ones described. Also, you should think of each health situation as permanent. Okay?

"The first description is the best health situation that you will be asked to rate; the second description is the worst. Here is the first one...

A. You can go anywhere, can move around freely wherever you are, have no restrictions on activity, and have no health problems. On a scale where 100 is good health and 0 is death what score would you give in this situation? SCORE _____

- B. Now, here is the second. You have to stay at a hospital or nursing home, have to be in bed or in a wheelchair controlled by someone else, need help to eat or go to the bathroom, and have losses of consciousness from seizures, blackouts or coma. Again, on a scale of 0 to 100, what score would you give in this situation? SCORE _____
DK/NA. . 999
- C. Moving on to other situations, you have to stay at a hospital or nursing home, have to be in bed or in a wheelchair controlled by someone else, and need help to eat or go to the bathroom, but have no other health problems SCORE _____
DK/NA. . 999
- D. You can be taken anywhere, but have to be in bed or in a wheelchair controlled by someone else, need help to eat or go to the bathroom, but have no other health problems. SCORE _____
DK/NA. . 999
- E. You can be taken anywhere, but have to be in bed or in a wheelchair controlled by someone else. Otherwise, you have no restrictions on activity and have no other health problems. SCORE _____
DK/NA. . 999
- F. You cannot drive a car or use public transportation, you have to use a walker or wheelchair under your own control, and are limited in the recreational activities you may participate in. You have no other health problems. SCORE _____
DK/NA. . 999
- G. You can be taken anywhere but you have to use a walker or a wheelchair under your own control, and are limited in the recreational activities you may perform, but have no other health problems . SCORE _____
DK/NA: . 999
- H. You can be taken anywhere, but you have to use a walker or a wheelchair under your own control. Otherwise, you have no restrictions on activity and have no other health problems SCORE _____
DK/NA. . 999
- I. You can go anywhere and have no limitations or other activity, but wear glasses or contact lenses. SCORE _____
DK/NA. . 999

Before we continue, I'd like to remind you that we are asking you to rate each health situation on a scale of 0 to 100, where 0 is death and 100 is good health. You may use any number from 0 to 100 for your rating.

- J. You can go anywhere and have no limitations on physical or other activity, but have pain or discomfort in your eyes or vision problems that corrective lenses can't fix. SCORE _____
DK/NA. . 999
- K. You can go anywhere and have no limitations on physical or other activity, but have stomach aches, vomiting or diarrhea SCORE _____
DK/NA. . 999
- L. You can go anywhere and have no limitations on physical or other activity, but have trouble falling asleep or staying asleep. SCORE _____
DK/NA. . 999
- M. You can go anywhere and have no limitations on physical or other activity, but have a bad burn over large areas of your body. SCORE _____
DK/NA. . 999
- N. You can go anywhere and have no limitations on physical or other activity, but are on prescribed medicine or a prescribed diet for health reasons. SCORE _____
DK/NA. . 999
- O. You can go anywhere and have no limitations on physical or other activity, but have drainage from your sexual organs and discomfort or pain. SCORE _____
DK/NA. . 999
- P. You can go anywhere and have no limitations on physical or other activity, but have trouble with sexual interest or performance SCORE _____
DK/NA. . 999
- Q. You can go anywhere and have no limitations on physical or other activity, but have pain in your ear or trouble hearing. SCORE _____
DK/NA. . 999
- R. You can go anywhere and have no limitations on physical or other activity, but have trouble learning, remembering or thinking clearly SCORE _____
DK/NA. . 999
- S. You can go anywhere. You have difficulty walking, but no other limitations on activity SCORE _____
DK/NA. . 999

As we continue, please remember we are asking you to rate each health situation on a scale of 0 to 100, where 0 is death and 100 is good health. You may use any number from 0 to 100 in your ratings.

- T. You can go anywhere. You have difficulty in walking because of a paralyzed or broken leg, but you have no other limitations on activity . . . SCORE _____
DK/NA. . 999
- U. You can go anywhere and have no limitations on physical or other activity, but you have trouble talking, such as a lisp, stuttering or hoarseness SCORE _____
DK/NA. . 999
- V. You can go anywhere and have no limitations on physical or other activity, but you can't stop worrying SCORE _____
DK/NA. . 999
- W. You can go anywhere and have no limitations on physical or other activity, but you have a painful or weak condition of the back or joints . . . SCORE _____
DK/NA. . 999
- X. You can go anywhere and have no limitations on physical or other activity, but you have an itchy rash over large areas of your body. SCORE _____
DK/NA. . 999
- Y. You can go anywhere and have no limitations on your physical or other activity, but you have pain while you are urinating or having a bowel movement. SCORE _____
DK/NA. . 999
- Z1. You can go anywhere and have no limitations on physical activity, but you have trouble with the use of drugs or alcohol. SCORE _____
DK/NA. . 999
- Z2. You can go anywhere and have no limitations on physical activity, but you have headaches or dizziness. SCORE _____
DK/NA. . 999
- Z3. You can go anywhere and have no limitations on physical or other activity, but you experience a lot of tiredness or weakness SCORE _____
DK/NA. . 999
- Z4. You can go anywhere and have no limitations on physical or other activity, but you are often depressed or upset SCORE _____
DK/NA. . 999
- Z5. You can go anywhere and have no limitations on physical or other activity, but you cough, wheeze or have trouble breathing SCORE _____
DK/NA. . 999

26. You can go anywhere and have no limitations on physical or other activity, but are overweight or have acne on your face

SCORE _____
DK/NA. . 999

Thank you for your ratings. Next, I have here a list of medical conditions. As I read each one, will you please tell me if you have had or presently have the condition? (INT: START WITH RED-CHECKED ITEM AND WORK YOUR WAY THROUGH ALL 30.)

<u>CONDITION</u>	<u>NO</u> <u>DK/NA NOT HAD</u>	<u>YES HAD</u> <u>OR HAVE</u>	<u>YES,</u> <u>MONTH</u> <u>YEARS</u>
1. You have been, at some time, unable to drive a car or use public transportation	1	2	3
2. You have used a walker or wheelchair under your own control	1	2	3
3. You have been limited in the recreational activities in which you participate.	1	2	3
4. You have experienced difficulty in walking because of a paralyzed or broken leg.	1	2	3
5. You have had stomach aches, vomiting or diarrhea.	1	2	3
6. You have had trouble falling asleep or staying asleep.	1	2	3
7. You have been overweight or have had acne on your face.	1	2	3
8. You have experienced pain in your ear or have had trouble hearing.	1	2	3
9. You have stayed in a hospital or in a nursing home	1	2	3
10. You have had trouble with the use of drugs or alcohol.	1	2	3
11. You have had drainage from your sexual organs and discomfort or pain.	1	2	3

<u>CONDITION</u>	<u>NO YES HAD</u>			<u>YES, MONTH</u>
	<u>DK/NA</u>	<u>NOT HAD</u>	<u>OR HAVE</u>	
12. You have had headaches or dizziness	1	2	3	_____
13. You have been in a bed or a wheelchair controlled by someone else.	1	2	3	_____
14. You have often felt depressed or upset	1	2	3	_____
15. You have had trouble learning, remembering or thinking clearly.	1	2	3	_____
16. You have experienced pain while urinating or having a bowel movement	1	2	3	_____
17. You have coughed, wheezed or had trouble breathing.	1	2	3	_____
18. You have had pain or weakness in your back or joints	1	2	3	_____
19. You have had an itchy rash over large areas or your body	1	2	3	_____
20. You wear glasses or contact lenses.	1	2	3	_____
21. You have had trouble with sexual interest or performance.	1	2	3	_____
22. You have had difficulty in walking.	1	2	3	_____
23. You have had trouble talking.	1	2	3	_____
24. You have been unable to stop worrying	1	2	3	_____
25. You have experienced pain or discomfort in your eyes or had vision problems that corrective lenses can't fix.	1	2	3	_____
26. You have been on prescribed medicine or a prescribed diet for health reasons	1	2	3	_____
27. You have had a bad burn over large areas of your body	1	2	3	_____
28. You have experienced a lot of tiredness or weakness.	1	2	3	_____

29. You have needed help in eating or going to the bathroom 1 2 3 | _____

30. You have had loss in consciousness due to seizures, blackouts or coma 1 2 3 | _____

Finally, a few questions about yourself. . .

31. Including yourself, how many persons are living in your immediate household?

NUMBER OF PERSONS
Refused 99

32. How many are 18 years or older?

NUMBER OF PERSONS
Refused 99

33. How many are under 18 years of age?

NUMBER OF PERSONS
Refused 99

34. We are interested in the level of health insurance coverage for Oregon families. Is anyone in your household presently covered by health insurance, that is, a health insurance plan which pays any part of a doctor or a hospital bill? Do not count Medicare, Medicaid or plans that pay only for accidents.

DK/NA 3
NO 2
YES 1

→ 34a. How many adults and children in your household are covered by this type of health insurance plan?

NUMBER COVERED _____

34b. Are there any adults or children in your household who are not covered by this type of health insurance?

DK/NA 1
NO 2
YES 3

→ 34c. How many adults or children in your household are not covered by this type of health insurance?

NUMBER _____

35. Incidentally, do you or anyone in your household carry a Medicaid card, or not?

- DK/NA. 1
- NO 2
- YES. 3

→ 35a. How many persons in your household are covered by Medicaid?

NUMBER COVERED _____

[INT: REFER TO Q 31 FOR THE TOTAL HH SIZE AND WRITE IT HERE. (____). THEN COMPARE THE INCOME LEVEL FOR THE HH SIZE IN THE TABLE BELOW AND ASK THE FOLLOWING QUESTION:]

36. By the way, is your total household income for 1989 above or below \$_____?

<u>HH SIZE</u>	<u>INCOME</u>	
1.....	\$ 6,000	ABOVE. 1
2.....	8,000	SAME 2
3.....	10,000	BELOW. 3
4.....	12,000	DK/NA. 4
5.....	14,000	
6.....	16,000	
7.....	18,250	
8.....	20,250	
9.....	22,250	
10.....	24,250	

37. Thinking back over the past 12 months, was there any time when you or someone in your household should have seen a doctor but for some reason did not?

- DK/NA 1
- NO. 2
- YES.. . . . 3

→ 37a. What do you feel is the main reason this person or persons did not see a doctor when they should have? (PROBE!)

What else? _____

38. Would you please tell me in (or near) which town or city you live?

TOWN OR CITY _____
Refused 999

39. Which one of these best describes your racial or ethnic heritage -- white, black, American Indian, Oriental or Hispanic?

- WHITE 1
- BLACK 2
- AMERICAN INDIAN . 3
- ORIENTAL. 4
- HISPANIC. 5
- Refused 6

40. One final question. What was your age on your last birthday?

YEARS . . . _____
 Refused . . . 99

41. Is there anything else you would like to tell us about your health or about health care in Oregon?

(THANK YOU FOR YOUR COOPERATION!)

(BY OBSERVATION):

42. R'S Sex?

- MALE 1
- FEMALE 2

Interviewer's Sig.

Date

This information is being requested to develop the expected outcomes of a given treatment. It is understood that some outcome data may be subjective in nature. A disease may be bimodal with significantly different outcomes occurring dependent on age of onset or vary according to the extent of the disease at the time of presentation (stage). If this is the case, please use two or more lines to define the condition. An attachment sheet accompanies this package to define the major categories to be evaluated. PLEASE THINK OF THE AVERAGE PATIENT THAT PRESENTS WITH THIS CONDITION, NOT THE EXTREMES. Any references or supporting documentation would be appreciated. Please contact the Commission staff at 378-6575 for any questions.

INSTRUCTIONS

ICD-9 Codes and Diagnosis

Please list both the ICD-9 code and a brief description. These may be grouped as much as possible.

CPT-4 and Procedure

Please list both the CPT-4 code used for treatment of this condition and a brief description. Group procedures that are similar in efficacy as much as possible. Please be prepared to identify any ancillary service (such as radiology, physical therapy) that may assist this procedure.

Median Age for this Treatment of the Condition

Please provide a median age for the this treatment of the condition. The cohort code listed on the attachment should be used if specific ages cannot be identified.

Probability that Treatment for the given Diagnosis will be Applied

Please provide your best estimate in percentages for the incidence of this treatment for the given condition.

Expected Duration of the Treatment Result

Please indicate the length of time that the treatment result will continue to be effective for the condition. If the beneficial effects persists for the future lifetime of the patient, indicate "LT".

Outcome Probability

Please provide your best estimation of the percent of the time that certain outcomes would occur five (5) years hence not given evaluated treatment and with treatment. The outcome expectations should not exceed 100% of the population for no treatment and with treatment.

The outcomes are:

1. Death
2. Residual Effects
3. Residual Effects
4. Residual Effects
5. Asymptomatic

The residual effects columns may be used to define health states intermediate to death and the return to prior health. Each column used must contain a single number designating the major symptom and may include up to three alpha codes, each one representing an impairment of physical or social activity and mobility. See attachments for major symptom and physical, social and mobility codes.

Cost

Please give your best estimate of the cost of the condition for the lifetime of the patient without the aforementioned treatment and with the treatment, if you are able.

THANK YOU FOR YOUR TIME AND INFORMATION

CODEMAJOR SYMPTOM

- 1.....Loss of consciousness such as seizure (fits), fainting, or coma (out cold or knocked out)
- 2.....Burn over large areas of face, body, arms or legs
- 3.....Pain, bleeding, itching, or discharge (drainage) from sexual organs - does not include normal menstrual (monthly) bleeding
- 4.....Trouble learning, remembering, or thinking clearly
- 5.....Any combination of one or more hands, feet, arms or legs either missing, deformed (crooked), paralyzed (unable to move), or broken - includes wearing artificial limbs or braces
- 6.....Pain, stiffness, weakness, numbness, or other discomfort in chest, stomach (including hernia or rupture), side, neck, back, hips, or any joints or hands, feet, arms, or legs
- 7.....Pain, burning, bleeding, itching, or other difficulty with rectum, bowel movements, or urination (passing water)
- 8.....Sick or upset stomach, vomiting or loose bowel movement, with or without fever, chills, or aching all over
- 9.....General tiredness, weakness, or weight loss
- 10.....Coughing, wheezing, or shortness of breath, with or without fever, chills, or aching all over
- 11.....Spells of feeling upset, being depressed or of crying
- 12.....Headache, or dizziness, or ringing in ears, or spells of feeling hot, or nervous, or shaky
- 13.....Burning or itching rash on large areas of face, body, arms, or legs
- 14.....Trouble talking, such as lisp, stuttering, hoarseness, or being unable to speak
- 15.....Pain or discomfort in one or both eyes (such as burning or itching) or any trouble seeing after correction
- 16.....Overweight for age and height or skin defect of face, body, arms, or legs, such as scars, pimples, warts, bruises, or changes in color
- 17.....Pain in ear, tooth, jaw, throat, lips, tongue; several missing or crooked permanent teeth - includes wearing bridges or false teeth; stuffy, runny nose; or any trouble hearing - includes wearing a hearing aid
- 18.....Taking medication or staying on a prescribed diet for health
- 19.....Wore eyeglasses or contact lenses
- 20.....Asymptomatic problem
- 21.....Has trouble falling asleep or staying asleep
- 22.....Has trouble with sexual interest or performance
- 23.....Is often worried
- 24.....Has trouble with the use of drugs or alcohol

*Revised from Robert M. Kaplan and John P. Anderson