

# Oregon's Survey of Public Health-State Preferences

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## *Introduction*

*One* of the unique aspects of Oregon's prioritization process is its attempt to incorporate the public's health care values and preferences. This appendix supplements chapter 3 by providing more detailed information on Oregon's effort to measure preferences for various health states. These measures were used along with treatment outcomes information to quantify a treatment's net benefit. As described in chapter 3, although it was an important conceptual component of the prioritization process, net benefit was ultimately not an important determinant of condition-treatment (CT) pair order on the list. Nonetheless, there is great interest in Oregon's incorporation of public preferences into outcomes assessment, and analyses of why Oregon's original attempt at a quantified cost-effectiveness approach to prioritization failed has focused attention on the Oregon Health Services Commission's (HSC) measurement of net benefit (54,90,1 10,249).

This appendix first very briefly describes the science of health-state preference measurement, emphasizing methods developed by Robert Kaplan and colleagues that were later adapted for Oregon's use. The comparability of preference weights as measured by Kaplan in California and the Oregon weights are examined. Next, inconsistent survey responses are examined, as are methods that could have been used to adjust weights. Lastly, the importance of differences in preference weights by various respondent characteristics are examined in more depth than is presented in chapter 3.

## *Measuring Health-State Preferences*

With attention increasingly focusing on treatments for chronic illness, outcome measures that describe treatment effects in terms of both mortality and morbidity and also incorporate public values associated with various outcomes are potentially very useful. Interventions such as heart transplants might increase life expectancy, but they may also seriously compromise highly valued aspects of life's quality such as physical functioning, mobility, and social activity. Indexes of quality of life try to capture, sometimes in a single measure, dimensions of health that affect its quality. Health-state preferences are measures of satisfaction or desirability that people associate with the presence of symptoms and functional limitations that can affect quality of life (73). Health-related quality of life measures are increasingly being considered for program evaluation, population monitoring, clinical research, and policy analysis.

Research has shown that people can make remarkably consistent subjective judgments, even when those judgments are abstract (74). Nonetheless, it is difficult to measure health-state preferences because:

- Individuals often make trade-offs (e.g., accept the side effects of a drug in order to reduce the risk of disease);
- Preferences may change over time; and
- Determining whose preferences to measure needs careful consideration when preferences are applied in a public policy context.

Investigators have defined different dimensions of health and have developed methods to measure their relative desirability. The three steps generally used to obtain health-state preferences are summarized very briefly below. There are several articles and texts available that comprehensively review the state of the art of defining and measuring health-state preferences (21,63,73,74,75,76,137,247,302).

### Step 1: Define Health and the Health Attributes To Be Measured

When operationalizing "quality of life," researchers often reference the World Health Organization's definition of health. It describes health as "a state of complete physical, mental, and social well-being and not merely the absence of infirmity" (315).

Examples of health attributes included in quality of life measures are shown in box C-1. For each attribute, levels can be defined that represent stepwise increments from good to poor functioning (e.g., no, mild or moderate, and severe pain). A range of health states can be described by selecting one level from each attribute. For the five health attributes shown in box C-1, for example, there are a total of 243 unique health states representing all possible combinations of levels (i.e., 3<sup>5</sup>). One example of such a health state is having mild to moderate limitations in physical functioning and emotional well-being, but no limitations in the other three attributes (i.e., social function, pain, cognitive ability).

### Step 2: Determine How Health States Should Be Presented to Respondents

There are several ways health states can be presented to respondents. One approach is to ask respondents to evaluate each unique combination of attribute levels (e.g.,

**Box C-1—Example of Quality-of-Life Health Attributes and Levels**

Attribute	Levels
• Physical function	No limitations Mild or moderate limitations Severe limitations
• Social function	No limitations Mild or moderate limitations Severe limitations
• Emotional well-being	No limitations Mild or moderate limitations Severe limitations
• Pain	No pain Mild or moderate pain Severe pain
• Cognitive ability	No limitations Mild or moderate limitations Severe limitations

SOURCE: Office of Technology Assessment, 1992.

243 in the example above).<sup>1</sup> This method has limitations because it is burdensome for respondents and it does not provide information about how the respondent weights and combines the attributes to arrive at their health-state preference. Alternative approaches allow investigators to estimate how important a particular attribute is to the assessment of the overall health state.

### Step 3: Determine How Respondents Are To Communicate Their Preferences

Several different techniques or scaling methods that are used to elicit health-state preferences from respondents are shown in box C-2. Frequently, respondents are asked to rate the desirability of each health state by placing it at some point on a scale between two anchors (e.g., from 0 to 100), usually representing death and perfect health. Alternatively, respondents might be asked to make a choice between alternative outcomes (e.g., see standard gamble and time trade-off techniques in box C-2).

### *The Quality of Well-Being Scale*

Oregon's Health Service Commission considered several health status or health preference measures before deciding to adapt the Quality of Well-Being (QWB) scale

(106).<sup>2,3</sup> The QWB Scale includes three attributes of daily functioning (i.e., mobility, physical activity, and social activity) and a list of 21 symptoms or problems that might inhibit function (table C-1). The mobility and physical activity attributes have three levels, while the social activity attribute has five levels. There are 945 possible combinations of symptoms/functional levels (i.e., 21 x 3 x 3 x 3 x 5). The developers of this model took the following steps to estimate the preference weights shown in table c-1:

- A stratified random sample of 343 case descriptions (unique combinations of the 21 symptom/problems, and mobility, physical activity and social activity levels) was divided into eight sets (about 40 case descriptions in each).
- A random sample (conducted in a 2-year period 1974-75) of 866<sup>4</sup> residents from the San Diego area was divided into eight groups of about 100 and asked during face-to-face interviews to rank the sets of health states on a 10-point scale.
- A mathematical model was used to estimate weights, representing the relative desirability of the health states on a scale from 0 (death) to 1 (good health).

An example of a QWB score for one individual at one point in time is shown in box C-3. In this example, the individual has one symptom (i.e., cough, wheezing, or shortness of breath) and is categorized by level on each of the three functional attributes (i.e., mobility, physical activity, and social activity). The component weights (all negative values) are subtracted from 1 (the score for perfect health) to yield the "point-in-time well-being score. Group QWB scores can be calculated as an average of the individual member's scores assessed for a particular day or a defined interval of time (107).

Prognosis, or the probability of moving between health states, has been integrated into the QWB model. While QWB as described above is a static or time-specific measure of function, the "well-life expectancy" is a dynamic measure. The "well-life expectancy" is the product of QWB and the expected duration of stay in each function level over a standard life period (Kaplan, R. M., and Anderson, J. P., 1988). Box C-4 shows an illustrative computation of group "well-life expectancy." The concept of well-years<sup>5</sup> or weighted life expectancy can be used to evaluate the effectiveness of programs and health

<sup>1</sup> Some of the possible health states can often be discarded on logical grounds. It is very unlikely, for example, that a person would experience severe pain and have no limitation of cognitive, social, or physical functions.

<sup>2</sup> A number of investigators have contributed to the development of the QWB scale, including J.W. Bush, D.L. Patrick, J.P. Anderson, and C.C. Berry (105). For simplicity, the model will be referred henceforth as the QWB model. Several articles referenced at the end of the appendix offer a more in-depth description of the QWB and its development.

<sup>3</sup> The HSC also considered the Sickness Impact Profile developed by Marilyn Bergner and a health service classification system developed by David C. Hadorn (194).

<sup>4</sup> A supplementary probability sample of 368 children was included (107).

<sup>5</sup> The term "Quality-Adjusted Life Years" (QALYs) is also used to describe the concept (107).

### Box C-2—Examples of Scaling Methods Used in Measuring Health-State Preferences

- . Standard gamble: The respondent chooses between a certain outcome and a gamble. This technique meets the requirements of certain decision theories that require preference judgments be made under conditions of uncertainty. The technique relies on a lengthy interview with well-trained interviewers using specially prepared props.
- . Time trade-off: The respondent is asked how much time (years of life) he or she would be willing to give up to be in a healthier state compared with a less healthy one. The technique relies on a lengthy interview with well-trained interviewers using specially prepared props.
- . Magnitude estimation: The respondent is given a standard health state and asked to provide a number or ratio indicating how much worse each of the other states is compared with the standard. This method is relatively easy to administer and easy for respondents to understand.
- . Rating scale: The respondent rates the desirability of each health state by placing it at some point on a scale (e.g., from 0 to 100) between two anchors, usually representing death and perfect health. The rating scale is the most frequently used method for measuring health-state preferences because it is relatively easy to administer and easy for respondents to understand.
- . Equivalence: The respondent decides how improvements of people in a specified health state are equivalent to improvements of people in the maximum health state. This method is infrequently used in studies of health preferences and is offensive to some.
- . Willingness-to-pay: The respondent decides what proportion of income he or she is willing to pay each week to get rid of a specified health condition or to have a specified probability of improving from a particular health state to perfect health. This technique has been used more often in cost-effectiveness analyses to measure the utility of reducing one's risk of dying than in studies to measure preferences for various health states.

SOURCE: D.G. Froberg and R.L. Kane, "Methodology for Measuring Health-State Preferences-II: Scaling Methods," *Journal of Clinical Epidemiology* 42(5):459-471, 1989.

interventions. Dividing the cost of a program by the well-years it yields gives a cost/utility ratio.

The QWB model is potentially useful because it provides a comprehensive expression of health status that simultaneously considers mortality and morbidity and considers both risks and benefits of treatments under evaluation (107).

### Oregon's Survey Content and Conduct

Oregon survey respondents rated a set of six functional states (e.g., needing help to eat or go to the bathroom)<sup>6</sup> and 23 health problems or symptoms (e.g., having stomach aches, vomiting or diarrhea) on a scale of 0 (representing

"as bad as death") to 100 (representing "good health"). A copy of the survey can be found at the end of this appendix. For each health situation presented, respondents were to assume that they had only the problems described and that the problems were permanent.

The functional states and health problems included on the Oregon survey were taken from Kaplan's California survey, but modified for telephone administration.<sup>7</sup> Telephone interviews took approximately 30 to 40 minutes. The Survey Research Center of Oregon State University at Corvallis administered the telephone survey in early 1990.<sup>8</sup> A random-digit dialing technique was used to reach a representative sample of the State's population.<sup>9</sup>

<sup>6</sup> The survey included two levels within three different attributes (i.e., mobility, physical activity, and social activity).

<sup>7</sup> The California survey had been administered in person--individuals completed written questionnaires after receiving instruction while in small groups. The Oregon Survey instrument was written at a sixth-grade reading level to help ensure oral comprehension of the questions. Oregon investigators completed a small pretest (less than 100 calls were made) to see if scores obtained by phone were consistent with scores obtained in California. The Oregon survey contained some items not on the California survey (i.e., four questions pertain to the use of drugs or alcohol, sexual performance, sleep disorders, and mental health).

<sup>8</sup> The survey was administered over a 2- to 3-week period.

<sup>9</sup> The sampling frame was provided to Oregon State University by a private consulting firm (135). Some regional weights were applied to the completed survey to correct for a small degree of sampling error. The responses were also weighted so that each adult in the survey had an equal chance of being selected. (If unweighted, adults in households with eight adults would only have a one-eighth chance of being selected for the survey, while adults in household with two adults would have a one-half chance of being selected.)

Table C-1-Quality of Well-Being Scale Weights

Levels/no.	Functional Limitations/Symptoms	Weights
<b>Mobility Scale (MOB)</b>		
5	<b>No</b> limitations for health reasons	<b>4.000</b>
4	<b>Did not drive a car, health related (younger than 16); did not ride in a car as usual for age, and/or did not use public transportation, health related; or had or would have used more help than usual forage to use public transportation; health related</b>	<b>-0.062</b>
2	<b>In hospital, health related</b>	<b>-0.090</b>
<b>Physical Activity Scale (PAC)</b>		
4	<b>No</b> limitations for health reasons	<b>-0.000</b>
3	<b>In wheelchair, moved or controlled movement of wheelchair without help from someone else; or had trouble or did not <b>try</b> to lift, stoop, bend over, or use stairs or inclines, health related, and/or limped, <b>used a cane, crutches or walker, health related;and/or had any other physical limitation in walking, or did not try to walk as far or as fast as others the same age are able, health related</b></b>	<b>-0.060</b>
1	<b>In wheelchair, did not move or control the movement of wheelchair without help from someone else, or in bed, chair, or couch for most or all of the day, health related</b>	<b>-0.077</b>
<b>Social Activity Scale (SAC)</b>		
5	<b>No</b> limitations for health reasons	<b>-0.000</b>
4	<b>Limited in other role activity, health related</b>	<b>-0.061</b>
3	<b>Limited in major (primary) role activity, health related</b>	<b>-0.061</b>
2	<b>Performed no major role activity, health related, but did perform self-care activities</b>	<b>-0.061</b>
1	<b>Performed no major role activity, health related, and did not perform or had more help than usual in performance of one or more self-care activities, health related</b>	<b>-0.106</b>
<b>Symptoms</b>		
1	<b>Death (not on respondent's card)</b>	<b>-0.727</b>
2	<b>Loss of consciousness such as seizure (fits), fainting, or coma (out cold or knocked out)</b>	<b>-0.407</b>
3	<b>Burn over large areas of face, body, arms, or legs</b>	<b>-0.367</b>
4	<b>Pain, bleeding, itching, or discharge (drainage) from sexual organs--does not include normal menstrual (monthly) bleeding</b>	<b>-0.349</b>
5	<b>Trouble learning, remembering, or thinking clearly</b>	<b>-0.340</b>
6	<b>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</b>	<b>-0.333</b>
7	<b>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, legs</b>	<b>-0.299</b>
8	<b>Pain, burning, bleeding, itching, or other difficulty with rectum, bowel movements, or urinations (passing water)</b>	<b>-0.292</b>
9	<b>Sick or upset stomach, vomiting or loose bowel movements, with or without fever, chills, or aching all over</b>	<b>-0.290</b>
10	<b>General tiredness, weakness, or weight loss</b>	<b>-0.259</b>
11	<b>Cough, wheezing, or shortness or breath with or without fever, chills, or aching all over</b>	<b>-0.257</b>
12	<b>Spells of feeling upset, being depressed, or of crying</b>	<b>-0.257</b>
13	<b>Headache, or dizziness, or ringing in ears, or spells or feeling hot, or nervous, or shaky</b>	<b>-0.244</b>
14	<b>Burning or itching rash on large areas of face, body, arms, or legs</b>	<b>-0.240</b>
15	<b>Trouble talking, such as lisp, stuttering, " hoarseness, or inability to speak</b>	<b>-0.237</b>
16	<b>Pain or discomfort in one or both eyes (such as burning or itching) or any trouble seeing after correction</b>	<b>-0.230</b>
17	<b>Overweight or underweight forage and height of skin defect of face, body, arms or legs, such as scars, pimples, warts, bruises, or changes in color</b>	<b>-0.186</b>
18	<b>Pain in ear, tooth, jaw, throat, lips, tongue; missing or crooked permanent teeth--includes wearing bridges or false teeth; stuffy, runny nose; any trouble hearing--includes wearing a hearing aid</b>	<b>-0.170</b>
19	<b>Taking medication or staying on a prescribed diet for health reasons</b>	<b>-0.144</b>
20	<b>Wore eyeglasses or contact lenses</b>	<b>-0.101</b>
21	<b>Breathing smog or unpleasant air</b>	<b>-0.101</b>
22	<b>No symptoms or problem (not on respondent's card)</b>	<b>-0.000</b>
23	<b>Standard symptom/problem (not on respondent's card)</b>	<b>-0.257</b>

SOURCE: R.M. Kaplan and J.P. Anderson, J. P., "The General Health Policy Model: An Integrated Approach," in *Quality Life Assessments in Clinical Trials*, B. Spilker (ed.) (New York, NY: Raven Press, 1990).

**Box C-3—Illustrative Computation of the Point-in-Time Well-Being Score**

Point-in-time well-being score for an individual (W):

$$W = 1 + (\text{Symptom wt}) + (\text{MOBwt}) + (\text{PACwt}) + (\text{SACwt}),$$

where wt is the preference-weighted measure for each symptom (symp), mobility limitation (MOB), physical activity limitation (PAC), and social activity limitation (SAC).

The W score for a person with the following description profile may be calculated for 1 day as follows:

Quality of well-being Level	Description	Weight
Symp-11	Cough, wheezing, or shortness of breath, with or without fever, chills, or aching all over.	-0.257
MOB-5	No limitations.	-0.000
PAC-1	In bed, chair, or couch for most or all of the day (health related).	-0.077
SAC-2	Performed no major role (health related) but did perform self care.	-0.061

$$W = 1 + (-0.257) + (-0.000) + (-0.077) + (-0.061) = 0.605$$

SOURCE: R.M. Kaplan and J.P. Anderson, "A General Health Policy Model: Update and Applications," *Health Services Research* 23(2):203-235, June 1988.

Approximately 4,500 calls were made to obtain 1,001 completed interviews.<sup>10</sup>

As an introduction to the telephone survey, interviewers told respondents that:

[The 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.

The interview consisted of six parts:<sup>11</sup>

1. Respondents rated the "best" and "worst" possible health states. These scores were expected to be the highest and lowest obtained throughout the interview. The "best" and "worst" health states presented were as follows:

*Best*

You can go anywhere, can move around freely wherever you are, have no restrictions on activity, and have no health problems.

*Worst*

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.

2. Respondents rated limitations in mobility (M1, M2), physical activity (P1, P2) and social activity (S1, S2) (see attached copy of the survey). The six questions were presented in a nested format. At first, respondents were told that they had a limitation in each of the three functional domains (i.e., M1,P1,S1 or M2,P2,S2). In subsequent questions one element was dropped, one at a time (e.g., M1,P1, and then M1).
3. Respondents rated 23 symptoms. Symptoms were asked about one at a time and not in combination with functional limitations.<sup>12</sup>
4. Respondents reported whether they had experienced the functional states or symptoms, and if so, for how long.
5. The following demographic information was obtained:
  - the number of persons living in the household and their age,<sup>13</sup>

<sup>10</sup> More than one-half of telephone numbers initially called were disconnected. Of the remaining calls, approximately one-fourth of people answering refused the interview and about one-fifth did not complete the interview. The characteristics of the nonrespondents are unknown because most hung up their telephones before descriptive information could be obtained.

<sup>11</sup> Interviewers informed respondents of the confidential and voluntary nature of the survey at the beginning of the interview.

<sup>12</sup> One exception to this was that "losses of consciousness from seizures, blackouts or coma" was included in the "worst" case scenario presented at the beginning of the interview.

<sup>13</sup> Number in household 18 years or older and under 18 years of age.

**Box C-4--Illustrative Computation of Well-Life Expectancy**

State	Years in State (Y)	Weight (W)	Weighted years (Y X W)
Well .....	65.2	1.00	65.2
Non-bed disability .....	4.5	.59	2.7
Bed disability .....	1.9	.34	.6
Current life expectancy .....			71.6 life years
Well-life expectancy .....			68.5 well-years

Suppose that a group of individuals was in a well state for 65.2 years, in a state of non-bed disability for 4.5 years, and in a state of bed disability for 1.9 years before their deaths at the average age of 71.6. In order to make adjustments for the diminished quality of life they suffered in the disability states, the duration of stay in each state is multiplied by the preference associated with the state. Thus, the 4.5 years of non-bed disability become 2.7 equivalents of well years when an adjustment is made for the preferences associated with being in that state. Overall, the well-life expectancy for this group is 68.5 years. The disability experienced by the group has reduced the quality of their lives by an estimated 3.1 years.

SOURCE: R.M. Kaplan and J.P. Anderson, "A General Health Policy Model: Update and Applications," *Health Services Research* 23(2):203-235, June 1988.

- . household members' health insurance coverage,
- . household income,
- . residence (county and town/city),
- . respondent's race/ethnicity, and
- respondent age.

6. In an open-ended format, respondents were asked if there were any household members who should have seen a doctor but for some reason did not, and if so, why the person did not see a doctor. Respondents were also given an opportunity to report anything about their health or about health care in Oregon.

Weights for the *functional states* were calculated somewhat differently. Respondents were asked to assign scores to combinations of mobility, physical, and social fictional states. The score for a particular functional state was calculated by subtracting the score assigned to the smaller set of functional states from the score assigned to the larger set of functional states (the sets differed by the inclusion of one functional state). The score for M2, for example, could be calculated by subtracting the score for the F2,S2 question (i.e., the question including functional states F2 and S2) from the M2,F2,S2 question (i.e., the question including all three functional states M2, P2, and S2).

**The Calculation of Preference Weights for Each Health State**

For each *symptom*, a *weight* was calculated as the average of the following individual scores:

$$\text{Health-state score} = \frac{-(\text{'Best' health-state score} - \text{Symptom score})/100^{14}}$$

If, for example, an individual scored the "best" health state as 90 and scored "trouble talking" as 72, the score for "trouble talking" for that respondent would be  $-(90-72)/100$  or  $-0.188$ . This value represents one individual's perception of the amount taken away from perfect health (score of 1) if he or she had trouble talking. <sup>15</sup>

QWB weights (i.e., the average of respondents' individual scores) for each function state and symptom are shown in box 3-D (chapter 3). The scores are expressed as negative values because they represent the amount associated with the condition that the public thinks should be subtracted from perfect health (score of 1). The functional limitation and health state that were perceived to detract least from perfect health were being unable to drive or use public transportation (-0.046) and wearing glasses or contact lenses (-0.055). The functional limitation and health state judged to detract most from perfect health were being confined to bed or in a wheelchair controlled by someone else (-0.560), and having trouble with the use of alcohol or drugs (-0.455). To describe a particular morbidity state, clinicians could assign up to

<sup>14</sup> The HSC incorrectly reported that individual "best" health state scores (and not 100) were used in the denominator (193).

<sup>15</sup> This method of calculating weights assumes an additive model for the preference function. Other researchers make the assumption of a multiplicative model (260).

four functional limitations or symptoms—one from each of the three categories of functional limitation and one symptom. (See chapter 3 for a description of how clinicians assigned the functional limitations and symptoms to CT pairs.)

### Reliability and Validity of Preference Weights

Preference measurements are assessed by examining their reliability and validity. A measure's reliability is the extent to which it gives consistent results. When intrarater reliability, for example, is high, it means that subjects respond consistently when an item is presented to them more than once over a short period of time. Investigators have shown that respondents give consistent QWB scale values when asked to repeat the task within several days (11). Inter-rater reliability reflects consistency of responses among different raters.

A measure's validity is the extent to which it corresponds to the "true" position of the person on the characteristic being assessed. There are different dimensions of validity. Content validity reflects the adequacy of the health-state descriptions in representing health status. Construct validity relates to the degree to which results of different scaling methods converge. Construct validity can also be evaluated by examining the degree to which predicted relationships between preferences and other variables are supported. Robert Kaplan and his colleagues have, for example, shown significant positive correlations between QWB weights and self-rated health, and negative correlations with age, number of chronic illnesses, symptoms, and physician visits (109).

Studies have shown that preference weights sometimes vary widely not only among individuals, as might be expected, but also with the format used for describing the health state, the framing of outcomes, the outcomes used to anchor the scale, the scaling task used, and other situation-specific factors (142). Mean values of grouped individual scores are generally used as weights, but there is considerable variation in ratings—some standard deviations from the Oregon survey approach 0.30 (see table 3-10 in chapter 3).<sup>16</sup> The variation of individual Oregon scores are of the same magnitude as is typically found in preference measures. Evidence suggests that while individuals within groups express differences in preference, preference weights are relatively constant from group to group (260). Using mean, or average, scores can be problematic because similar mean scores from two groups could obscure two very dissimilar score profiles (141). At the extreme, one group could unanimously rate being confined to a wheelchair as .5 while in another, one-half

could rate it 0 (as bad as death) and the remainder as 1 (as good as perfect health). The mean scores from these two groups would be identical.

While some evidence suggests that certain preference scales, including the QWB scale, are reliable and valid (211), it is generally agreed that more research is needed in this area (141). Further research could, among other things, show how predictive preferences are of patient decisionmaking and how and why preferences might change over time (142).

### Comparison of Kaplan's and Oregon's Methods and Resultant Weights

There are several important differences between Kaplan's and Oregon's method of obtaining health-state preference weights:

- In Oregon, the interviews were conducted by telephone, while in California they were conducted in person.
- Kaplan presented respondents with health-state scenarios that included combinations of functional limitations and symptoms. Oregon combined some of the functional limitations in "nested" questions, but all but one of the symptoms (i.e., coma, fainting) were presented to respondents one at a time.
- Survey questions differed substantially in length and substance. Table C-2 shows Kaplan's descriptions of health states alongside of those as defined in Oregon. Questions were shortened for Oregon's telephone survey, but sometimes this significantly altered the description of the health state. For example, Kaplan's survey included the health state "trouble talking such as lisp, stuttering, hoarseness, *or being unable to speak.*" This was abbreviated to "have trouble talking, such as a lisp, stuttering or hoarseness" on the Oregon survey.<sup>17</sup>
- The two instruments included different health states. Oregon included four questions regarding the use of drugs and alcohol, sexual performance, sleep problems, and worrying which were not included on the Kaplan survey. Kaplan included a question on "major" role activity (e.g., work) and air pollution not included on the Oregon survey.
- The assumed duration of the health state differed in the two surveys. Kaplan asked respondents to give their preferences while imagining that the health state was experienced *on a particular day*. Oregon respondents were told to imagine the health states described as *permanent*.

<sup>16</sup> The standard deviation is a measure of dispersion from a mean score. A standard deviation as large as 0.30 for a distribution of health preferences on a 0 to 1 scale indicates that respondents differ greatly in their preferences (75).

<sup>17</sup> During Kaplan's face-to-face interviews, the health states were initially presented to respondents on small cards in an abbreviated format. Before rating the health state, the respondents read the more lengthy description of the health state (105).

**Table C-2-Comparison of Oregon and Kaplan Health-State Weights**

Oregon	Oregon weight	Kaplan et al.	Kaplan weight
<b>Function limitations</b>			
<i>Mobility</i>			
Have to stay at hospital or nursing home	-0.049	In hospital, health related	-0.090
Cannot drive a car or use public transportation	-0.046	Did not drive a car, health related (younger than 16); did not ride in a car as usual for age, health related; and/or did not use public transportation, health related; or had or would have used more help than usual for age to use public transportation, health related	-0.062
<i>Physical activity</i>			
Have to use a walker or wheelchair under your own control	-0.373	In wheelchair, moved or controlled movement of wheelchair without help from someone else; or had trouble or did not try to lift, stoop, bend over, or use stairs or inclines, health related; and/or limped, used a cane, crutches, or walker, health related; and/or had any other physical limitation in walking, or did not try to walk as far or as fast as others the same age are able, health related	-0.060
Have to be in bed or in a wheelchair controlled by someone else	-0.560	In wheelchair, did not move or control the movement of wheelchair without help from someone else, or in bed, chair, or couch for most or all of the day (health related)	-0.077
<i>Social activity</i>			
Are limited in the recreational activities you may participate in	-0.062	Limited in other (e.g., recreational) role activity (health related)	-0.061
_____	—	Limited in major (primary) role activity (health related)	-0.061
_____	—	Performed no major role activity (health related) but did perform selfcare activities	-0.061
Need help to eat or go to the bathroom	-0.106	Performed no major role (health related) and did not perform or had more trouble than usual in performance of one or more self-care activities (health related)	-0.106
<b>Health states/symptom</b>			
Have losses of consciousness from seizures, blackouts or coma	-0.14	Loss of consciousness such as seizure (fits), fainting, or coma (“out cold” or “knocked out”)	-0.407
Wear glasses or contact lenses	-0.55	Wore eyeglasses or contact lenses	-0.101
Have pain or discomfort in your eyes or vision problems that corrective lenses can’t fix	-0.248	Pain or discomfort in one or both eyes (such as burning or itching) or any trouble seeing after correction	-0.230
Have stomach aches, vomiting or diarrhea	-0.370	Sick or upset stomach, vomiting, or loose bowel movement, with or without fever, chills, or aching all over	-0.290
Have trouble falling asleep or staying asleep	-0.248	_____	—
Have a bad burn over large areas of your body	-0.372	Burn over large areas of face, body, arms or legs	-0.367

Are on prescribed medicine or a prescribed diet for health reasons	-0.120	Taking medication or staying on a prescribed diet for health reasons	-0.144
Have drainage from your sexual organs and discomfort or pain	-0.325	Pain, bleeding, itching, or discharge (drainage) from sexual organs—does not include normal menstrual (monthly) bleeding	-0.349
Have trouble with sexual interest or performance	-0.276	_____	—
Have pain in your ear or trouble hearing	-0.217	Pain in ear, tooth, jaw, throat, lips, tongue; missing or crooked permanent teeth—includes wearing bridges or false teeth; stuffy, runny nose; or any trouble hearing—includes wearing a hearing aid	-0.170
Have trouble learning, remembering or thinking clearly	-0.367	Trouble learning, remembering, or thinking clearly	-0.340
Have difficulty in walking because of a paralyzed or broken leg, but you have no other limitations on activity	-0.277	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	-0.333
Have trouble talking, such as a lisp, stuttering or hoarseness	-0.188	Trouble talking such as lisp, stuttering, hoarseness, or being unable to speak	-0.237
Can't stop worrying	-0.215	_____	—
Have a painful or weak condition of the back or joints	-0.253	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	-0.299
Have an itchy rash large areas of your body	-0.297	Burning or itching rash on large areas of face, body, arms, or legs	-0.240
Have pain while you are urinating or having a bowel movement	-0.299	Pain, burning, bleeding, itching, or other difficulty with rectum, bowel movements, or urination (passing water)	-0.292
Have trouble with the use of drugs or alcohol	-0.455	_____	—
Have headaches or dizziness	-0.305	Headache, dizziness, ringing in ears, or spells of feeling hot, nervous, or shaky	-0.244
Experience a lot of tiredness or weakness	-0.275	General tiredness, weakness, or weight loss	-0.259
Are often depressed or upset	-0.326	Spells of feeling upset, being depressed, or crying	-0.257
Cough, wheeze or have trouble breathing	-0.318	Cough, wheezing, or shortness of breath with or without fever, chills, or aching all over	-0.257
Overweight or have acne on your face	-0.215	Overweight or underweight for age and height or skin defect of face, body, arms, or legs such as scars, pimples, warts, bruises, or changes in color	-0.186
_____	—	Breathing smog or unpleasant air	-0.101

SOURCES: Oregon Department of Human Resources, Office of Medical Assistance Programs, Salem, OR, *The Oregon Medicaid Demonstration Waiver Application*, submitted to the Health Care Financing Administration, Aug. 16, 1991; R.M. Kaplan and J.P. Anderson, "The General Health Policy Model: An Integrated Approach," in B. Spilker (ed.), *Quality Life Assessments in Clinical Trials* (New York, NY: Raven Press, 1990); R.M. Kaplan and J.P. Anderson, "A General Health Policy Model: Update and Applications," *Health Services Research* 23(2):203-235, June 1988.

- Different methods were used to calculate the average population weight. Oregon used subtraction to estimate weights (e.g., for nested questions, the value of health state C was determined by subtracting the value of health state AB from health state ABC), while Kaplan used a regression model to estimate weights.
- Kaplan completed his survey in the mid-1970s, while Oregon's survey was completed in early 1990.

A comparison of the preference weights obtained in California and Oregon show that many are similar (see table C-2). More than one-half (i.e., 15 of 27 health states that can be compared) of the California and Oregon weights do not vary by more than 20 percent. There are, however, three health states with extremely different weights:<sup>18</sup>

- Have to use a walker or wheelchair under your own control (-0.373 Oregon vs. -0.060 California);
- Have to be in bed or in a wheelchair controlled by someone else (-0.560 Oregon vs. -0.077 California); and
- Have losses of consciousness from seizures, black-outs, or coma (4).114 Oregon vs. -0.407 California).

A possible explanation for these three extreme differences in weights lies in how weights for these three items were calculated in Oregon. The health state "have to be in a bed or in a wheelchair controlled by someone else" was the last health state in the first series of nested questions presented on the survey (see questions B, C, D, and E of the survey). The series of nested questions can be described as follows:

- Question B—WXYZ
- Question C—WXY
- Question D—WX
- Question E—W.

The weight for Y was estimated by subtracting the values of question D from question C. Similarly, the weight for Z was estimated by subtracting the value of question C from question B. Three of the 4 functional limitations have incremental values assigned to them. That is, the weight for Z represents the added decrement over and above having just X and Y. In contrast health state W in question E (e.g., the bed/wheelchair item) was assessed relative to the "best" health state. Its value is calculated as the difference between the value for question E and the value assigned to "best" health. The other Oregon functional limitation weight that deviates from Kaplan's is "have to use a walker or wheelchair under your own control." It, too, is presented singly following the second series of nested questions (i.e., questions F, G,

and H) and its weight is relative to "best" health rather than to the presence of other functional limitations.

The deviant score for the "losses of consciousness and coma" health state could also be explained by its presentation to respondents. Rather than being described to respondents by itself as the other symptoms' are (i.e., questions I through Z6), it is presented as part of a nested question (question B) and its weight is calculated relative to question C and not to the "best" health state. All other symptom weights were calculated relative to "best" health.

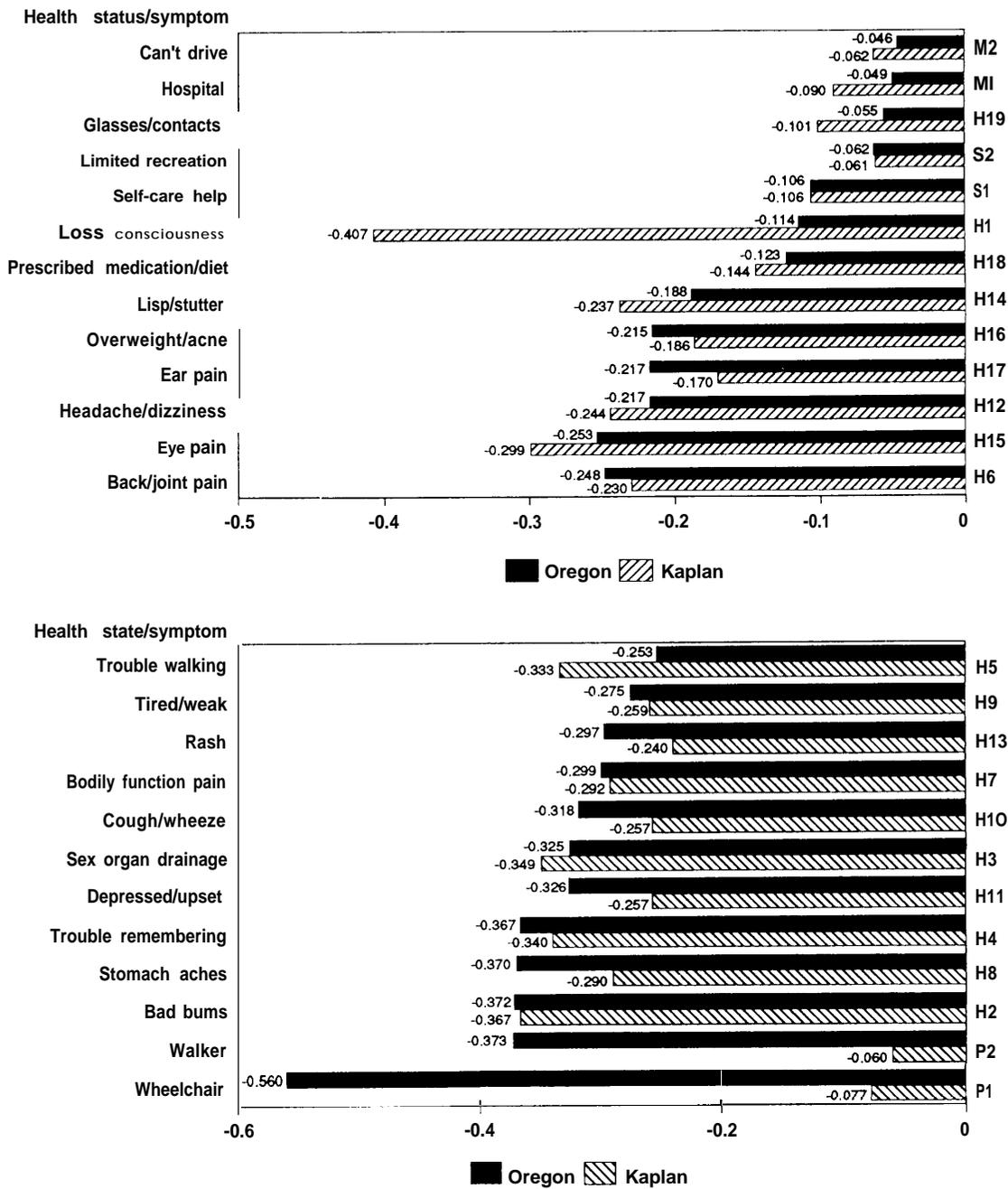
Aside from these three extreme differences, most of the preference weights in California are comparable to Oregon weights (i.e., more than one-half of Oregon's weights are within 20 percent of California weights) (see figure C-1). Given the differences in survey content and methods, these similarities are actually surprising. Oregon respondents were told to assume that the health states described were *permanent*, while California respondents were to try and imagine the health state at *one point in time* or one day. It is counterintuitive, for example, that Oregon respondents would rate *permanently* "experiencing pain while urinating or having a bowel movement" similar to California respondents experiencing this symptom *at a point in time* (Oregon -.299 vs. California -.292). It may be that respondents generally ignored the instructions regarding duration of the health state and imagine them as permanent or temporary according to their own experience. Some of the descriptive information on the California survey probably helped respondents consider the health state as temporary. In the description of "cough and wheezing and shortness of breath" and of "sick or upset stomach, vomiting, or loose bowel movement," the California survey included "with or without fever, chills, or aching all over," symptoms almost universally experienced as temporary. In these two cases, the California weights were considerably more favorable than Oregon weights (i.e., -0.257 vs. -0.318 and -0.290 vs. -0.370) (table C-2).

#### Methods of Adjusting Weights for Inconsistent Responses and Respondents' Sociodemographic and Health Characteristics

More than one-third (38 percent) of Oregon respondents provided some logically inconsistent responses to the survey. This section describes the nature of inconsistent responses and proposes methods that could have been used to adjust preference weights for these inconsistencies. Adjusted weights are then compared to Oregon weights and the effect of using these new weights on the ranking of CT pairs is assessed. Next, the importance of differences in preference weights by sociodemographic and health characteristics is assessed. The preference

<sup>18</sup> For simplicity, the wording from the Oregon survey is shown here. See table C-2 for differences in health-state description.

Figure C-I-Comparison of Oregon and Kaplan Health-State Weights



SOURCES: Oregon Health Services Commission, Salem, OR, unpublished data provided to the Office of Technology Assessment in 1991; R.M. Kaplan and J.P. Anderson, "The General Health Policy Model: An Integrated Approach," *Quality of Life Assessments in Clinical Trials*, B. Spilker (ed.) (New York, NY: Raven Press, 1990).

**Table C-3-Frequency of Ratings of the “Best” and “Worst” Health States Described in the Survey**

Best health state (Q1)	Worst health state (Q2)											Total	
	0	1-9	10-19	20-29	30-39	40-49	50-59	60-69	70-79	80-89	90-99		100
0 ..													0
1-9 .....													0
10-19 .....	1												1
20-29 .....	1			1	1	1	1						5
30-39 .....													0
40-49 .....													0
50-59 .....	11		2	4	1	1	3				1	1	24
60-69 .....	3		2	1		1	1	2					10
70-79 .....	9	1	8	16	1	1	3	1	1			1	41
80-89 .....	11	7	8	13	4	3	7		1		1		55
90-99 .....		22	16	18	13	6	2	5	2	2		0	86
100 .....	343	109	127	103	33	18	43	2		2	1	1	782
Total .....	401	133	165	151	46	26	63	7	2	4	3	3	1,004 <sup>a</sup>

<sup>a</sup> Sum exceeds sample size of 1,001 because of weighting by county and household composition.

SOURCE: Office of Technology Assessment, 1992. Based on analyses of Oregon Health Services Commission telephone survey data.

**Figure C-2—Health-State Boundaries Set by Survey Responses to Q<sub>1</sub> and Q<sub>2</sub>**



SOURCE: Office of Technology Assessment, 1992. Based on data from the Oregon Health Services Commission.

weights for some health states, for example, vary significantly by experience of the health state. Analyses are presented showing how condition-treatment (CT) pair placement on the list would change if only selected subgroups of respondents' weights were used.

**The Origin of Inconsistent Scores**

Respondents were told early in the interview how to scale their responses to the survey. A score of zero was to be given to a state “as bad as death,” a score of 100 to states representing “good health,” and a score of 50 to health states halfway between death and good health. Survey respondents were then given the opportunity to provide a personal “boundary” for their health-state scores when they answered the first two questions on the survey and rated the “best” and “worst” health states. This technique is often used in measuring health-state preferences. Sometimes, interviewers construct a “ther-

момeter’ with respondent’s upper and lower scores to remind the respondent what the logical range of responses are for subsequent questions.

Table C-3 shows that most respondents gave low scores to the “worst” and high scores to the “best” health states.<sup>19</sup> One-third (34 percent) of respondents had a range of values of 100—they assigned a value of 0 to the “worst” and 100 to the “best” health state. Some respondents, however, had very narrow boundaries—5 percent provided a range of values of 50 or less (e.g., a score of 50 to 59 for the “worst” health state and a score of 80 to 89 for the “best” health state). Figure C-2 shows the “boundaries” respondents set in responding to the “best” and “worst” health-state questions.

Thirteen percent of respondents gave a score of less than 100 (e.g., 70) to the “best” health state, but later rated health states such as experiencing ear pain higher

<sup>19</sup> More than three-quarters (78 percent) of respondents valued the “best” health state as 100 and 40 percent valued the “worst” state as 0.

**Table C-4—Frequency of Inconsistent Responses to Survey Used To Assess Health-State Preferences**

	Nest 1 + 2 <sup>a</sup> consistent	Nest 1 or 2 inconsistent	Both nest 1 + 2 inconsistent	Total
No boundary inconsistency . . . . .	620	148	15	783
Left-sided inconsistent <sup>b</sup> . . . . .	42	29	14	85
Right-sided inconsistency <sup>c</sup> . . . . .	61	26	7	94
Both left- and right-sided inconsistency . . . . .	9	24	6	39
<b>Total . . . . .</b>	<b>732</b>	<b>227</b>	<b>42</b>	<b>1,001</b>

a Nest 1 refers to the first set of functional limitation questions that include limitations M1, P1, and S1. Nest 2 refers to the second set of functional limitation questions that include limitations M2, P2, and S2. (See questionnaire at the end of this appendix.)

b Left-sided inconsistencies refer to health-state scores that are lower than those assigned to the "worst" health state.

c Right-sided inconsistencies refer to health-state scores that are higher than those assigned to the "best" health state.

SOURCE: Office of Technology Assessment, 1992. Based on analyses of Oregon Health Services Commission telephone survey data.

(e.g. 90). For discussion purposes, health-state scores that are assigned higher scores than the "best" health state will be referred to as "right-sided boundary violations." Twelve percent of respondents gave health-state scores that were lower than that given to the "worst" health state (e.g. rating the "worst" health state as 40 and then rating "having stomach aches, vomiting or diarrhea" as 30). These health-state scores will be referred to as "left-sided boundary violations." Table C-4 shows the frequency of these boundary violations. At the extreme, eight respondents (1 percent of the total) gave a lower score to the "best" health state than to the "worst" health state.

Health-state scores are positive when there are right-sided boundary violations. This can be seen by again examining the way health-state scores are calculated:

Health-state score =

$$\bullet ( \text{'Best' health-state score} - \text{Symptom score} ) / 100$$

These positive scores have the effect of bringing the health-state weights<sup>20</sup> which vary from 0 (perfect health) to -1 (death) closer to 0 or perfect health.

The most likely explanation for the boundary violations is that respondents forgot the value assigned to the "best" and "worst" health states when they were later asked to value particular health states.<sup>21</sup> Conceivably, when respondents assigned a health state a lower value than that assigned to the "worst" health state, they may have been indicating a health state that they indeed felt was worse than that health state. That any of the health states represent states better than good health seems less plausible. Table C-5 shows the extent to which inconsistent responses were provided for each health state, and table C-6 shows the number of inconsistent responses over the course of the interview. More than 1 in 10 (12

percent) of respondents provided at least 5 responses inconsistent with their "best" and "worst" health-state boundaries.

A second type of inconsistency occurred in response to the nested functional limitation questions. More than one-quarter (27 percent) of respondents provided inconsistent responses to one or both of the nested questions. One example of such a response is giving a less favorable score to a health state defined by one functional limitation (e.g., used a wheelchair) than to a health state including that and an additional limitation (e.g., used a wheelchair and needed help going to the bathroom or eating). One possible explanation for these inconsistent responses is that respondents may have been confused by the length of some of the nested questions (see survey questions B through H). Respondents can process simultaneously only five to nine pieces of information (140) and some of the questions may exceed this threshold.

When respondents with either type of inconsistent response are eliminated, the sample size is reduced from 1,001 to 620 (table C-4). The HSC decided to use all values from the survey, despite the logical inconsistencies of some responses, because it reported that the deletion of inconsistent responses did not greatly affect the health-state weights and it wanted to maintain the total sample, which was representative of the State's population.

Weights of consistent as compared with inconsistent respondents are shown in table C-7 and are graphed in figure C-3. There are statistically significant differences for all but five weights when consistent and inconsistent respondents are compared (table C-7). Figure C-3 shows that the two sets of weights, although different, are highly correlated (correlation coefficient = 0.98).

<sup>20</sup> Health-state weights are the average of individual health-state scores.

<sup>21</sup> The interviewer did not remind respondents of their earlier responses.

**Table C-5--Frequency of Inconsistent Responses to the Survey Used To Develop Preference Weights**

		Percent of time respondents rated larger number of functional limitations as better than a smaller subset of those functional limitations	
<b>Components of "nested" functional/imitation questions</b>			
<b>1st nested question</b>			
M1.	Have to stay at hospital or nursing home . . . . .		18.6
P1.	Have to be in bed or in a wheelchair controlled by someone else		
S1.	Need help to eat or go to the bathroom		
H1.	Experience loss of consciousness due to seizures, blackouts or coma		
<b>2nd nested question</b>			
M2.	Cannot drive a car or use public transportation . . . . .		12.5
P2.	Have to use a walker or wheelchair under your own control		
S2.	Are limited in the recreational activities you may participate in		
		Percent of time rated better than "best" health state	Percent of time rated worse than "worst" health state
<b>Health states/symptoms</b>			
H2.	Have a bad burn over large areas of your body. . . . .	2.9	4.5
H3.	Have drainage from your sexual organs and discomfort or pain . . . . .	2.3	3.2
H4.	Have trouble learning, remembering or thinking clearly . . . . .	3.4	3.5
H5.	Have difficulty in walking because of a paralyzed or broken leg, but you have no other limitations on activity. . . . .	4.7	1.9
H6.	Have a painful or weak condition of the back or joints. . . . .	4.1	2.2
H7.	Have pain while you are urinating or having a bowel movement . . . . .	3.0	3.3
H8.	Have stomach aches, vomiting or diarrhea. . . . .	2.7	3.1
H9.	Experience a lot of tiredness or weakness . . . . .	3.2	2.2
H10.	Cough, wheeze or have trouble breathing . . . . .	2.6	2.6
H11.	Often depressed or upset. . . . .	3.0	3.0
H12.	Have headaches or dizziness . . . . .	3.2	3.4
H13.	Have an itchy rash over large areas of your body . . . . .	3.1	2.4
H14.	Have trouble talking, such as a lisp, stuttering or hoarseness . . . . .	5.8	1.7
H15.	Pain or discomfort in your eyes or vision problems that corrective lenses can't fix. . . . .	4.7	2.1
H16.	Overweight or have acne on your face . . . . .	5.4	1.9
H17.	Have pain in your ear or trouble hearing . . . . .	4.4	1.9
H18.	Are on prescribed medicine or a prescribed diet for health reasons . . . . .	7.7	1.0
H19.	Wear glasses or contact lenses . . . . .	10.7	0.7
H20.	Have trouble falling asleep or staying asleep . . . . .	5.1	2.3
H21.	Have trouble with sexual interest or performance . . . . .	3.0	3.3
H22.	You can't stop worrying . . . . .	5.6	2.3
H23.	Have trouble with the use of drugs or alcohol. . . . .	2.1	5.9

SOURCE: Office of Technology Assessment, 1992. Based on analyses of Oregon Health Services Commission telephone survey data.

**Table C-6-Frequency of Scores Reported as Better or Worse than Scores Assigned to the Best and Worst Health State (Q1 and Q2)<sup>a</sup>**

Number of scores better than score assigned to the best health state (Q1)	Number of scores worse than score assigned to the worst health state (Q2)								Total
	0	1	2	3	4	5	6-9	10-26	
0 . . . . .	783	33	10	7	5	6	8	18	869
1 . . . . .	12	0	0	1	0	2	3	0	17
2 . . . . .	9	0	1	0	0	0	0	0	10
3 . . . . .	11	2	2	0	0	1	0	0	15
4 . . . . .	3	0	2	0	0	1	0	1	7
5 . . . . .	10	0	0	0	0	0	2	0	11
6-9 . . . . .	19	3	0	0	1	0	1	2	25
10-26 . . . . .	29	6	1	2	0	2	3	4	46
<b>Total . . . . .</b>	<b>876</b>	<b>43</b>	<b>15</b>	<b>9</b>	<b>6</b>	<b>10</b>	<b>16</b>	<b>24</b>	<b>1,000</b>

<sup>a</sup>Row and column cells may not add to totals because of sample weighting.

SOURCE: Office of Technology Assessment, 1992. Based on analyses of Oregon Health Services Commission telephone survey data.

Table C-7—Differences in Preference Weights According to Consistency of Respondent<sup>a</sup>

Functional limitations/symptoms	Consistent respondents	Inconsistent respondents
Cannot drive a car or use public transportation (M2) . . . . .	-0.052	-0.036
Are limited in the recreational activities you may participate in (S2) . . . . .	-0.062	-0.063
Have to stay at hospital or nursing home (M1) . . . . .	-0.070	-0.015 <sup>b</sup>
Wear glasses or contact lenses (H19) . . . . .	-0.083	-0.008 <sup>b</sup>
Need help to eat or go to the bathroom (S1) . . . . .	-0.112	-0.097
Experience loss of consciousness due to seizures, blackouts or coma (H1) . . . . .	-0.117	-0.110
Have trouble talking, such as a lisp, stuttering or hoarseness (H14) . . . . .	-0.203	-0.163 <sup>b</sup>
Have pain in your ear or trouble hearing (H17) . . . . .	-0.232	-0.191 <sup>b</sup>
Overweight or have acne on your face (H16) . . . . .	-0.232	-0.187 <sup>b</sup>
You can't stop worrying (H23) . . . . .	-0.242	-0.170 <sup>b</sup>
Have trouble falling asleep or staying asleep (H21) . . . . .	-0.262	-0.225 <sup>b</sup>
Pain or discomfort in your eyes or vision problems that corrective lenses can't fix (H15) . . . . .	-0.270	-0.210 <sup>b</sup>
Have difficulty in walking because of a paralyzed or broken leg, but you have no other limitations on activity (H5) . . . . .	-0.276	-0.216 <sup>b</sup>
Have a painful or weak condition of the back or joints (H6) . . . . .	-0.281	-0.208 <sup>b</sup>
Have trouble with sexual interest or performance (H22) . . . . .	-0.287	-0.258
Experience a lot of tiredness or weakness (H9) . . . . .	-0.294	-0.243 <sup>b</sup>
Have an itchy rash over large areas of your body (H13) . . . . .	-0.315	-0.269 <sup>b</sup>
Have pain while you are urinating or having a bowel movement (H7) . . . . .	-0.316	-0.273 <sup>b</sup>
Have headaches or dizziness (H12) . . . . .	-0.322	-0.276 <sup>b</sup>
Cough, wheeze or have trouble breathing (H10) . . . . .	4.337	-0.288 <sup>b</sup>
Have drainage from your sexual organs and discomfort or pain (H3) . . . . .	-0.339	-0.301 <sup>b</sup>
Often depressed or upset (H11) . . . . .	-0.354	-0.281 <sup>b</sup>
Have a bad burn over large areas of your body(H2) . . . . .	-0.384	-0.354 <sup>b</sup>
Have stomach aches, vomiting or diarrhea(H8) . . . . .	-0.387	-0.343 <sup>b</sup>
Have trouble learning, remembering or thinking clearly . . . . .	-0.395	-0.321 <sup>b</sup>
Have to use a walker or wheelchair under your own control (P2) . . . . .	-0.409	-0.314 <sup>b</sup>
Have trouble with the use of drugs or alcohol (H24) . . . . .	-0.474	-0.424 <sup>b</sup>
Have to be in bed or in a wheelchair controlled by someone else (P1) . . . . .	-0.613	-0.472 <sup>b</sup>

<sup>a</sup> Consistent respondents (n = 620) are those who made no boundary violations and who had consistent responses to the nested questions. Inconsistent respondents (n = 381) made either boundary violations or provided inconsistent responses to the nested questions.

<sup>b</sup> Differences between consistent and inconsistent weights are significant (p = .02) as assessed by t-tests.

SOURCE: Office of Technology Assessment, 1992. Based on analyses of Oregon Health Services Commission telephone survey data.

Comparing those who made none with those who made at least one inconsistent response shows that respondents who are Medicaid recipients, low income, and racial/ethnic minority group members were significantly more likely to have provided inconsistent responses. One-half of respondents with incomes at or below the poverty level, for example, provided some inconsistent responses, while 37 percent of those with higher incomes provided inconsistent responses.

#### Adjusted Weights

Adjustments could have been made for inconsistent responses. The assumption could be made that when respondents assigned a higher score to a symptom than to the “best” health state that they viewed their upper boundary as 100. Similarly, one could assume that when respondents assigned a lower score to a symptom than to the “worst” health state that they viewed their lower boundary as 0. Nine percent of respondents made only right-sided violations, 9 percent made only left-sided

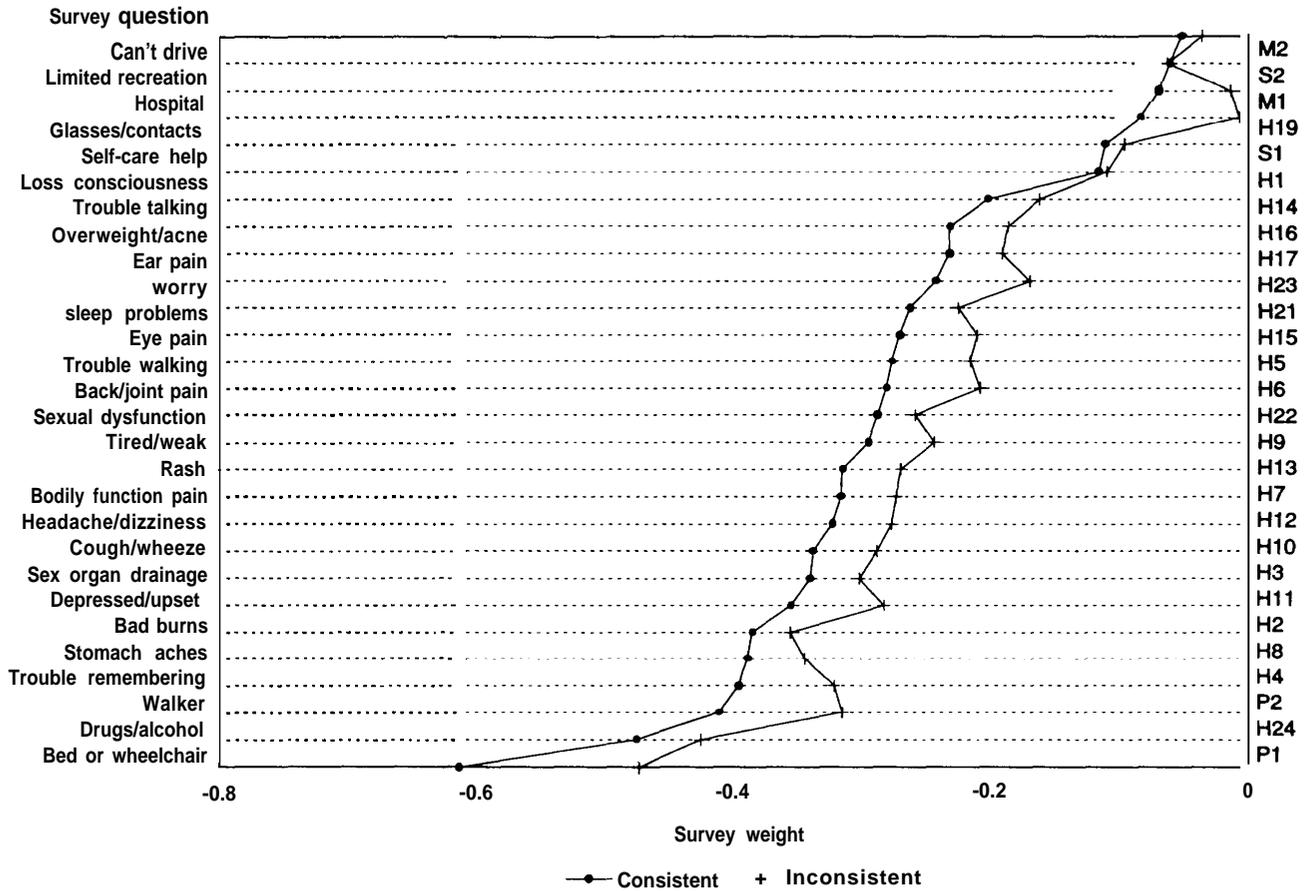
violations, and 4 percent made both left- and right-sided violations (see table C-4). Assigning 100 to the “best” health state if respondents made any right-sided errors and zero to the “worst” health state if respondents made any left-sided errors, using the respondents’ range of responses as the denominator,<sup>22</sup> and eliminating inconsistent responses to the nested functional state questions yields the weights shown in the second column of table C-8. In general, these scores are lower than the weights actually used (shown in the first column).

The respondent’s boundary was ignored when the health-state score was calculated (see formula above). The Oregon weights were calculated with 100 as a denominator, which assumes that the range of values for health states was 100 for everyone. For those with ranges of values less than 100, the use of 100 effectively decreases the weight assigned to the health state.

Another way to adjust for inconsistent responses is to assume that responses to question 1 should have been 100

<sup>22</sup> The Oregon weights were calculated using 100 as the denominator, even though 22 percent of respondents rated the ‘best’ health state as less than 100.

Figure C-3-Survey Weights of Consistent and Inconsistent Respondents



SOURCE: Office of Technology Assessment, 1992. Based on data from the Oregon Health Services Commission.

and the range of values from best and worst health state is 100. These adjusted weights, shown in the third column of table C-8, also tend to be lower than those that were used (shown in the first column).

To test whether the adjustment of weights is important, the ranking of (CT pairs (by category and within category by net benefit) using adjusted and unadjusted weights was compared. When adjustments are made for inconsistent responses using the first method (i.e., using weights in the second column of table C-8),<sup>23</sup> the resultant change in weights shifts the relative placement of 49 CT pairs (7 percent) by 10 or more lines relative to the ranking expected when unadjusted weights are used to rank CT pairs. Despite these shifts, there would have been no changes in CT pair coverage with line 587 defining coverage.

#### Differences in Weights by Sociodemographic and Health-State Experience

There are numerous significant differences in preference weights according to respondent sociodemographic characteristics and health-state experience (see table 3-11 in ch. 3). That Oregon's preference weights varied by sociodemographic and health experience should not be surprising. Kaplan and his colleagues report negative correlations between individual's QWB scores and age, number of chronic medical conditions, number of reported symptoms or problems, number of physician contacts, and dysfunctional status (109). After reviewing the literature, Froberg concluded that age and experience with the health state being rated may influence rater's valuations, but that the effects of most other demographic and experiential variables (e.g., sex, religion, marital status) are small or nonexistent (75). Analyses of the

<sup>23</sup> The weights in the first column of table C-7 are adjusted for right and left-sided boundary violation and exclude inconsistent responses to the nested questions.

**Table C-8—Health-State Preference Weights Calculated by Different Methods**

Functional limitations/symptoms	Oregon weights <sup>a</sup>	OTA adjusted method 1 <sup>b</sup>	OTA adjusted method 2 <sup>c</sup>
<b>Mobility</b>			
M1. Have to stay at hospital or nursing home . . . . .	-0.049 (0.137)	-0.077 (0.104)	-0.069 (0.096)
M2. Cannot drive a car or use public transportation . . . . .	-0.046 (0.1 12)	-0.065 (0.093)	-0.059 (0.086)
<b>Physical activity</b>			
P1. Have to be in bed or in a wheelchair controlled by someone else . . . . .	-0.560 (0.257)	-0.653 (0.224)	-0.609 (0.223)
P2. Have to use a walker or wheelchair under your own control . . . . .	-0.373 (0.246)	-0.447 (0.232)	-0.417 (0.222)
<b>Social activity</b>			
S1. Need help to eat or go to the bathroom . . . . .	-0.106 (0.146)	-0.121 (0.134)	-0.110 (0.1 23)
S2. Are limited in the recreational activities you may participate in . . . . .	-0.062 (0.099)	-0.071 (0.092)	-0.064 (0.085)
<b>Health states/symptoms</b>			
H1. Have losses of consciousness from seizures, blackouts or coma . . . . .	-4.114 (0.175)	-0.128 (0.141)	-0.114 (0.129)
H2. Have a bad burn over large areas of your body , . . . . .	-0.372 (0.265)	-0.448 (0.263)	-0.420 (0.251)
H3. Have drainage from your sexual organs and discomfort or pain . . . . .	-0.325 (0.240)	-0.395 (0.243)	-0.372 (0.236)
H4. Have trouble learning, remembering or thinking clearly . . . . .	-0.367 (0.235)	-0.444 (0.228)	-0.414 (0.216)
H5. Have difficulty in walking because of a paralyzed or broken leg, but you have no other imitations on activity . . . . .	-0.253 (0.210)	-0.319 (0.210)	-0.299 (0.200)
H6. Have a painful or weak condition of the back or joints . . . . .	-0.253 (0.210)	-0.317 (0.202)	-0.300 (0.196)
H7. Have pain while you are urinating or having a bowel movement . . . . .	-0.299 (0.236)	-0.366 (0.236)	-0.346 (0.228)
H8. Have stomach aches, vomiting or diarrhea. . . . .	-0.370 (0.239)	-0.444 (0.235)	-0.418 (0.227)
H9. Experience a lot of tiredness or weakness . . . . .	-0.275 (0.201)	-0.341 (0.197)	-0.321 (0.190)
H10. Cough, wheeze or have trouble breathing . . . . .	-0.318 (0.224)	-0.390 (0.223)	-0.366 (0.21 3)
H11. Are often depressed or upset . . . . .	-0.326 (0.234)	-0.399 (0.229)	-0.374 (0.218)
H12. Have headaches or dizziness . . . . .	-0.305 (0.221)	-0.373 (0.218)	-0.352 (0.212)
H13. Have an itchy rash over large areas of your body . . . . .	-0.297 (0.227)	-0.364 (0.223)	-0.344 (0.216)
H14. Have trouble talking, such as a lisp, stuttering or hoarseness . . . . .	-0.188 (0.202)	-0.245 (0.197)	-0.234 (0.1 89)
H15. Have pain or discomfort in your eyes or vision problems that corrective lenses can't fix. . . . .	-0.248 (0.212)	-0.311 (0.203)	-0.294 (0.195)
H16. Are overweight or have acne on your face . . . . .	-0.215 (0.227)	-0.273 (0.225)	-0.260 (0.21 5)
H17. Have pain in your ear or trouble hearing . . . . .	-0.217 (0.204)	-0.277 (0.202)	-0.263 (0.196)
H18. Are on prescribed medicine or a prescribed diet for health reasons . . . . .	-0.123 (0.183)	-0.175 (0.180)	-0.169 (0.1 71)
H19. Wear glasses or contact lenses . . . . .	-0.055 (0.166)	-0.098 (0.153)	-0.099 (0.148)
H20. Have trouble falling asleep or staying asleep . . . . .	-0.248 (0.218)	-0.312 (0.217)	-0.295 (0.206)
H21. Have trouble with sexual interest or performance . . . . .	-0.276 (0.246)	-0.341 (0.256)	-0.323 (0.247)
H22. Can't stop worrying . . . . .	-0.215 (0.216)	-0.277 (0.214)	-0.261 (0.204)
H23. Have trouble with the use of drugs or alcohol . . . . .	-0.455 (0.290)	-0.537 (0.284)	-0.502 (0.275)

a Weights as reported by Oregon Health Services Commission.  
 b Adjusted weights calculated by assigning 100 to the "best" health state if respondents made any right-sided errors and 0 to the "worst" health State if respondents made any left-sided errors, using the respondents range of responses as the denominator, and eliminating inconsistent responses to the nested functional state questions.  
 c Adjusted weights calculated by assigning 100 to responses to Q1.

SOURCE: Office of Technology Assessment, 1992. Based on analyses of Oregon Health Services Commission telephone survey data.

Oregon survey data using multivariate techniques show that respondent age and experience with the health state often significantly affect the weights, respondent sex,

race/ethnicity, and residence sometimes affect the weights; and that Medicaid participation and poverty do not affect the weights.

<sup>24</sup> Analysis of variance was used to assess the unique effects of respondent sociodemographic and health experience characteristics controlling for other factors (see table 3-11 inch. 3).

Table C-9-Differences in Preference Weights According to Respondent Health-State Experience

Functional limitations/symptoms	No experience	Experience
	weight (number)	weight (number)
Cannot drive a car or use public transportation (M2) . . . . .	-0.044(826)	-0.056(173)
Have to stay at hospital or nursing home (M1) . . . . .	-0.056(556)	-0.041 (441)
Are limited in the recreational activities you may participate in (S2). . . . .	-0.062(679)	-0.063(321)
Wear glasses or contact lenses (H19) . . . . .	-0.078(310)	-0.044(689)
Need help to eat or go to the bathroom (S1) . . . . .	-0.104(956)	-0.147 (40)
Experience loss of consciousness due to seizures, blackouts or coma (H1) . . . . .	-0.116(937)	-0.082 (59)
Have trouble talking, such as a lisp, stuttering or hoarseness (H14). . . . .	-0.189(970)	-0.155 (31)
You can't stop worrying (H23) . . . . .	-0.218(820)	-0.205(170)
Have pain in your ear or trouble hearing (H17) . . . . .	-0.222(684)	-0.204(315)
Overweight or have acne on your face(H16). . . . .	-0.233(552)	-0.192(438)
Pain or discomfort in your eyes or Vision problems that corrective lenses can't fix (H15), . . . . .	-0.251 (910)	-0.216 (85)
Have trouble falling asleep or staying asleep (H21) . . . . .	-0.259(651)	-0.230(343)
Have difficulty in walking because of a paralyzed or broken leg, but you have no other limitations on activity(H5). . . . .	-0.260(857)	-0.214(141)
Have a painful or weak condition of the back or joints (H6) . . . . .	-0.265(473)	-0.243(525)
Experience a lot of tiredness or weakness (H9). . . . .	-0.282(761)	-0.253(235)
Have trouble with sexual interest or performance(H22) . . . . .	-0.284(886)	-0.207 (85)
Have an itchy rash overlarge areas of your body(H13) . . . . .	-0.302(831)	-0.273(166)
Have pain while you are urinating or having a bowel movement (H7) . . . . .	-0.308(787)	-0.266(204)
Have headaches or dizziness (H12) . . . . .	-0.324(607)	-0.276(388)
Often depressed or upset (H11) . . . . .	-0.329(738)	-0.319(256)
Have drainage from your sexual organs and discomfort or pain (H3) . . . . .	-0.330(882)	-0.290(107)
Cough, wheeze or have trouble breathing (H10) . . . . .	-0.338(700)	-0.271 (294)
Have a bad burn over large areas of your body (H2) . . . . .	-0.372(960)	-0.399 (30)
Have trouble learning, remembering or thinking clearly . . . . .	-0.375(874)	-0.314(122)
Have to use a walker or wheelchair under your own control (P2) . . . . .	-0.385(922)	-0.238 (78)
Have stomach aches, vomiting or diarrhea(H8) . . . . .	-0.387(617)	-0.346(381)
Have trouble with the use of drugs or alcohol (H24) . . . . .	-0.460(902)	-0.396 (74)
Have to be in bed or in a wheelchair controlled by someone else (P1) . . . . .	-0.564(926)	-0.504 (74)

SOURCE: Office of Technology Assessment, 1992. Based on analyses of Oregon Health Services Commission telephone survey data.

Of some concern are the 12 significant differences in preference scores by health-state experience (see table 3-11 in ch.3). For all of the 12 differences, respondents who had experienced the health state viewed it more favorably than those who had not. Table C-9 and figure C-4 show the weights of respondents with and without health-state experience. Although different, the two sets of weights are highly correlated (correlation coefficient =0.96)

If ranking had been determined by category and net benefit within category and the preference weights of those having experienced the health state in question had been used instead of average weights, there would have been shifts in CT pair placement on the list. A total of 45 CT pairs (6 percent) would shift up or down the list by 10 or more lines relative to the placement expected if average scores were used. Following these shifts, six CT pairs would change coverage status with coverage set at line 587 (three would move up to be covered, three would move down to lose coverage).

Because those who have experienced a symptom or functional limitation view it as less burdensome than those who have nonexperienced it, applying the "experience" weights usually has the effect of shifting the CT pair down the list. Take, for example, a treatment for a

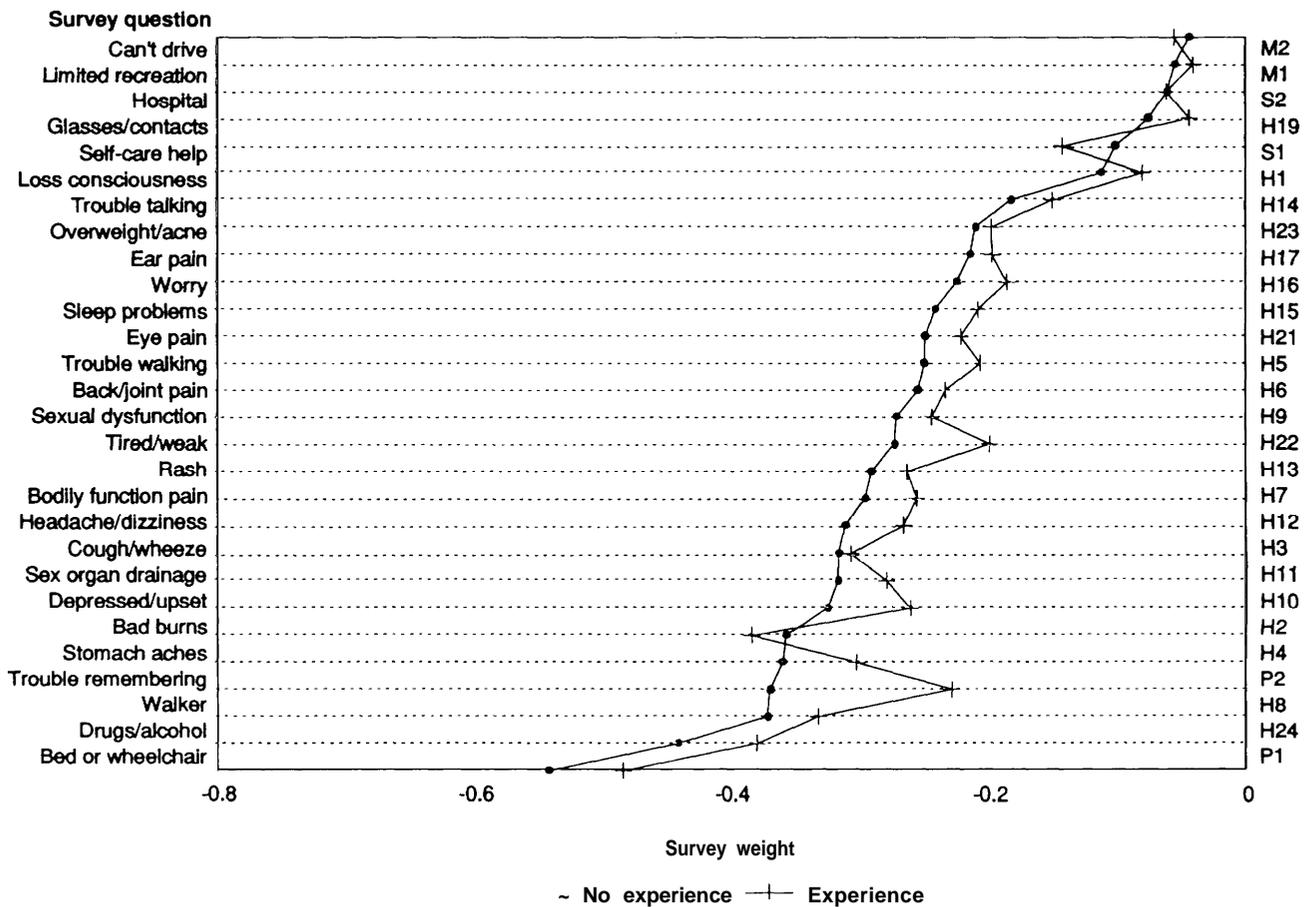
condition that improves mobility and reduces the probability that a patient would need to use a walker or wheelchair following treatment. This reduced chance of reliance on a walker or wheelchair is valued more by those never having experienced their use. If weights of those with experience with wheelchairs and walkers are used, this CT pair would move down the list.

Given the significant differences in some weights by sex (see table 3-1 1), it may be appropriate to selectively apply women's or men's weights to conditions that only affect one sex. Applying women's weights for the symptoms "drainage from sexual organs" and "sexual dysfunction" to dysmenorrhea (CT pair 574), which is characterized by these symptoms, for example, shifts this CT pair down the list 10 lines. Women view these symptoms more favorably than men do. Box C-5 shows how the calculation of net benefit for the dysmenorrhea CT pair is affected by using men's and women's weights.

## Summary

The science of defining and measuring health-state preferences is evolving and is important because there is an increasing need to assess health care interventions in terms of mortality and morbidity, taking into account public preferences for various morbidity states. Measures

Figure C-4-Survey Weights of Respondents With and Without Health-State Experience



SOURCE: Office of Technology Assessment, 1992. Based on data from the Oregon Health Services Commission.

of health-state preference have been incorporated into the design of clinical trials, and their analyses show that the ability to detect a treatment's effectiveness is sometimes improved when quality-of-life measures are used (108).

Oregon conducted a survey to assess public health-state preferences and used the preference weights from this survey to assess the net benefit of the 709 treatments on the prioritized list. In the final prioritization scheme used by the HSC, the quantified net benefit term that included consideration of patient preferences was not an important determinant of CT pair order. There has, however, been considerable debate as to whether the preferences as assessed in Oregon could be used as a part of a prioritization process.

OTA concludes that the public health-state preferences as assessed in Oregon should not yet be used as part of a prioritization process for the following reasons:

- More than one-third of respondents provided inconsistent responses to the survey. Respondents who were poor, Medicaid recipients, or members of racial/ethnic minority groups were more likely to give inconsistent responses. The extent of inconsistent responses may indicate that respondents were not able to comprehend the content of the survey by phone. Most of the preferences of consistent respondents were significantly different from those of inconsistent respondents, but the two sets of weights are highly correlated. When adjustments are made for inconsistencies, the weights change and when applied to the list, significantly change the order of 7 percent of CT pairs (i.e., change the order by 10 or more lines).
- There is considerable person-to-person variation in preferences, as evidenced by relatively large standard deviations associated with mean weights. Some of this variation can be explained by differences in preferences according to characteristics such as age,

**Box C-5-Calculating Net Benefit Using Women's vs. Men's Weights for the Condition-Treatment (CT) Pair Dysmenorrhea**

<i>Women's weights</i>										
State	Without treatment					With treatment				
	pa	FL/S <sup>b</sup>	Weight <sup>c</sup>	QoL value <sup>d</sup>	(P X Value)	pa	FL/S <sup>b</sup>	Weight <sup>c</sup>	QoL value <sup>d</sup>	(P X Value)
1. Death . . . . .	0.00	—	-1.000	0.000	0.0000	0.00	—	-1.000	0.000	0.0000
2. Morbidity state 1 . . . . .	0.90	H3	-0.3071	0.6929	0.62361	0.20	H3	-0.3071	0.6929	0.13858
3. Morbidity state 2 . . . . .	0.10	H22	-0.2557	0.7443	0.07443	0.05	H22	-0.2557	0.7443	0.037215
4. Morbidity state 3 . . . . .	—	—	—	—	—	—	—	—	—	—
5. Perfect health . . . . .	0.00	—	0.000	1.000	0.0000	0.75	—	0.000	1.000	0.7500
Σ (P x QoL value) . . . . .					0.69804					0.925795

<i>Men's weights</i>										
State	Without treatment					With treatment				
	pa	FL/S <sup>b</sup>	Weight <sup>c</sup>	QoL value <sup>d</sup>	QoL (P X value)	pa	FL/S <sup>b</sup>	Weight <sup>c</sup>	QoL value <sup>d</sup>	QoL (P X value)
1. Death . . . . .	0.00	—	-1.000	0.000	0.0000	0.00	—	-1.000	0.000	0.0000
2. Morbidity state 1 . . . . .	0.90	H3	-0.3510	0.6490	0.5841	0.20	H3	-0.3510	0.6490	0.1298
3. Morbidity state 2 . . . . .	0.10	H22	-0.3059	0.6941	0.06941	0.05	H22	-0.3059	0.6941	0.034705
4. Morbidity state 3 . . . . .	—	—	—	—	—	—	—	—	—	—
5. Perfect health . . . . .	0.00	—	0.000	1.000	0.0000	0.75	—	0.000	1.000	0.7500
Σ (P X QoL Value) . . . . .					0.65351					0.914505

NOTE: Net benefit is the difference between the value of Σ (P x QoL value) for patients with and without treatment. For women, the net benefit is .925795 -0.69504 = 0.227755. For men, the net benefit is 0.914505465351 - 0.260995.

a P = probability of being in state.

b FL/S = functional limitation/symptom associated with health state (see box 3-D for description of health states).

c Weight = the weight the public assigns to the functional limitation/symptom. Can be interpreted as the amount taken away from perfect health (valued as 1) associated with the presence of a functional limitation/symptom. Weights for all telephone survey items are shown in box 3-D.

d QoL value = quality of life value = (1 + weight). When there is more than one functional limitation or symptom assigned to the health state, weights are added before summing to 1. Can be interpreted as the value associated with the state on a scale from 0 (death) to 1 (perfect health).

SOURCE: Office of Technology Assessment, 1992. Based on data from the Oregon Health Services Commission.

sex, and whether the respondent had experienced the condition in question. When average weights of subpopulations are applied (e.g., women, those with experience with the health state), the order of selected CT pairs changes significantly (i.e., by 10 or more lines).

- Oregon used an adaptation of the QWB scale to assess health-state preferences. The majority of health states as measured by Oregon and Kaplan are similar. This finding is surprising, given that California respondents were asked to consider the health state in question at one point in time while Oregon respondents were to consider the health state to be permanent. The literature suggests that duration of a health state dramatically affects preference (234). It is possible that respondents in both California and Oregon disregarded the instructions and gave preferences using their own frame of reference.
- An examination of a possible cause of three extreme differences in health-state preference between California and Oregon respondents points to a possible limitation in how preferences are calculated. There appear to be differences in preferences when health states are measured as compared with “best” health versus as compared with another symptomatic health state.

In light of the extent of inconsistent responses, the Oregon weights should have been adjusted before being incorporated into the net benefit calculation. The inconsistencies in responses are troublesome, especially as

inconsistent respondents were more likely to have been low income, Medicaid recipients, and members of racial/ethnic minority groups. Nonetheless, if one assumes that the inconsistencies do not reflect total incomprehension of the survey, corrections could have been made to minimize their effect.

The second issue, that preference weights differ significantly by sociodemographic and health characteristics, is more troubling. In light of the finding that using different weights for certain CT pairs (e.g., women's weights for dysmenorrhea) alters CT pair order on the list, careful consideration might be given to when subpopulation weights should be applied. It may be that finding such differences invalidates the premise that health preferences are universally held and hence the use of such weights at all.

The last issue identified, that many of the preference weights estimated by Kaplan and Oregon are similar when they should probably be different, points to potential limitations in the underlying method. It may be that respondents cannot articulate preferences while simultaneously considering externally defined prognosis or duration of the health state.

In light of these issues, OTA concludes that much additional research is needed to validate health-state preference instruments and measurement techniques before they can be used as part of resource allocation decisions.

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 \_\_\_\_\_  
DK/NA. . 999

- 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 a n 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 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>	NO YES HAD			YES, MONTH YEARS
	<u>DK/NA</u>	<u>NOT HAD</u>	<u>OR HAVE</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>				YES,
	DK/NA!	NO NOT HAD	YES HAD OR HAVE	<b>MONT'</b> YEAR.
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 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!)

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(BY OBSERVATION) :

- 42. R'S Sex? M A L E . . . . . 1
- FEMALE . . . . . 2

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\_\_\_\_\_  
Interviewer's Sig.

\_\_\_\_\_  
Date