

**Kidney Disease Quality of Life Short Form (KDQOL-SF<sup>tm</sup>), Version 1.3:  
A Manual for Use and Scoring**

**Ron D. Hays  
Joel D. Kallich  
Donna L. Mapes  
Stephen Joel Coons  
Naseem Amin  
William B. Carter  
Caren Kamberg**

RAND is a nonprofit institution that helps improve public policy through research and analysis. Papers are issued by RAND as a service to its professional staff. They are personal products of the authors rather than the results of sponsored RAND research. They have not been formally reviewed or edited. The views and conclusions expressed in Papers are those of the authors and are not necessarily shared by other members of the RAND staff or by its research sponsors. For more information or to order RAND documents, see RAND's URL (<http://www.rand.org>) or contact Distribution Services, RAND, 1700 Main Street, P.O. Box 2138, Santa Monica, CA 90407-2138, phone (310) 451-7002; Fax: (310) 451-6915; Internet: [order@rand.org](mailto:order@rand.org).

Published 1997 by RAND  
1700 Main Street, P.O. Box 2138, Santa Monica, CA 90407-2138  
1333 H St., N.W., Washington, D.C. 20005-4792

KIDNEY DISEASE QUALITY OF LIFE SHORT FORM (KDQOL-SF™), Version 1.3:  
A Manual for Use and Scoring

---

Written by:

Ron D. Hays  
Joel D. Kallich  
Donna L. Mapes  
Stephen Joel Coons  
Naseem Amin  
William B. Carter

Development of the KDQOL™ measure was supported by an unrestricted research grant from Amgen to RAND, and a subgrant from the University of Arizona to RAND. The measures were developed for use in the "Enhancing the Role of Pharmacists in the Care of Chronic Dialysis Patients Through the Use of Computer-modeled Algorithms for Epogen Dosing" research project sponsored by Amgen through a grant to the University of Arizona (S. J. Coons, PI). The KDQOL-SF™ 1.3 was constructed for use in the Renal Outcomes Study, sponsored by Baxter Healthcare Corporation. Development of the KDQOL-SF™ 1.3 was supported by additional grants from Baxter Healthcare Corporation and from Amgen.

RAND hereby grants permission to use the KDQOL-SF™ 1.3 in accordance with the following conditions which shall be assumed by all to have been agreed to as a consequence of accepting and using this document:

1. The user of the KDQOL-SF™ 1.3 accepts full responsibility, and agrees to indemnify and hold RAND harmless, for the accuracy of any translations of the KDQOL-SF™ 1.3 into another language and for any errors, omissions, misinterpretations, or consequences thereof.
2. The user of the KDQOL-SF™ 1.3 accepts full responsibility, and agrees to indemnify and hold RAND harmless, for any consequences resulting from the use of the KDQOL-SF™ 1.3.
3. The user of the KDQOL-SF™ 1.3 will provide a credit line when printing and distributing this document acknowledging that its development was supported in part by an unrestricted grant from Amgen to RAND, a subgrant from the University of Arizona to RAND, and a grant from Baxter Healthcare Corporation. The following citation is suggested:  
  
Hays, R. D., Kallich, J. D., Mapes, D. L., Coons, S. J., Amin, N., & Carter, W. B. (1995). *Kidney Disease Quality of Life Short Form (KDQOL-SF™), Version 1.3: A Manual for Use and Scoring*. Santa Monica, CA: RAND, P-7994.
4. No further written permission is needed for use of the KDQOL-SF™ 1.3.

# KIDNEY DISEASE QUALITY OF LIFE SHORT FORM (KDQOL-SF™), Version 1.3: A Manual for Use and Scoring

---

## CONTENT OF THE KDQOL-SF™ 1.3

The Kidney Disease Quality of Life (KDQOL™) Instrument is a self-report measure developed for individuals with kidney disease and on dialysis (Hays, Kallich, Mapes, Coons, & Carter, 1994). Despite the outstanding psychometric performance of the KDQOL™, some investigators may be reluctant to use it because of its length. This document summarizes the selection of a short-form item set for the kidney disease-targeted portion of the KDQOL™. The KDQOL-SF™ 1.3 includes 43 kidney-disease targeted items as well as 36 items that provide a generic core and an overall health rating item. KDQOL-SF™ 1.3 differs from KDQOL-SF™ 1.2 by adding a screening item about sexual activity.

The KDQOL-SF™ 1.3 disease-targeted items focus on particular health-related concerns of individuals with kidney disease and on dialysis: Symptom/problems (12 items), Effects of kidney disease on daily life (8 items), Burden of kidney disease (4 items), Work status (2 items), Cognitive function (3 items), Quality of social interaction (3 items), Sexual function (2 items), and Sleep (4 items). Also included are three additional quality of life scales: Social support (2 items), Dialysis staff encouragement (2 items), and Patient satisfaction (1 item). The KDQOL-SF™ 1.3 also includes a 36-item health survey (RAND 36-Item Health Survey 1.0 or SF-36™) as the generic core (Hays, Sherbourne, & Mazel, 1993; Ware & Sherbourne, 1992), consisting of eight multi-item measures of physical and mental health status: physical functioning (10 items), role limitations caused by physical health problems (4 items), role limitations caused by emotional health problems (3 items), social functioning (2 items), emotional well-being (5 items), pain (2 items), energy/fatigue (4 items), and general health perceptions (5 items). The final item, the overall health rating item, asks respondents to rate their health on a 0-10 response scale ranging from "worst possible (as bad or worse than being dead)" to "best possible health."

The 80 KDQOL-SF™ 1.3 items (see items 1-24b in the Appendix) take about 16 minutes to complete. A recommended set of background items is also provided (see items 25-38 in the Appendix).

## FIELD TESTING

To "learn the vocabulary and discover the thinking pattern" of those with kidney disease (Krueger, 1988, p. 39), we conducted three focus groups with patients and one focus group with staff at dialysis centers. The first focus group included three males and one female currently on hemodialysis (two had tried peritoneal dialysis previously and three had had transplants). The second group consisted of three females and one male (one female left early because her ride was waiting). This patient population had a diversity of kidney disease history: three were currently on hemodialysis (two had renal transplants previously, one had tried peritoneal dialysis) and one was on peritoneal dialysis (and had had a transplant). The third group consisted of four females and one

male, all currently on peritoneal dialysis (two had had a transplant and two had been on hemodialysis). All focus groups were run using a standardized protocol with open-ended questions and discussion.

Comments from focus group participants indicated that many were tired and had trouble concentrating on dialysis days. Several participants indicated that in the beginning they had overly optimistic expectations about how they would feel before starting dialysis (they thought that the machine would "return them to normal"). All were very sick and nauseous when they first started dialysis, but over time nausea became less common and they developed strategies for coping with the treatment and symptoms (e.g., eating only donuts before dialysis, eating saltines to settle the stomach). A common theme among participants was that kidney disease reduced the number of "good hours" in their day, thereby diminishing the quality of their life. In addition, focus group members often stated that they did most of the same activities as other people, but they just do less of them on a given day and did them more slowly. They emphasized the importance of moderation and acceptance of their limitations.

Based on these focus group interviews and a review of the literature on quality of life among kidney disease patients (e.g., Kurtin et al., 1992; Kurtin & Nissenson, 1993; Kutner, Brogan, Kutner, 1986; Laupacis et al., 1991; Levin, Lazarus, & Nissenson, 1993; Whittington, Barradell, & Benfield, 1993), we designed the KDQOL™.

The KDQOL™ includes multi-item scales targeted at particular health-related concerns of individuals with kidney disease and on dialysis: Symptom/problems (34 items), Effects of kidney disease on daily life (20 items), Burden of kidney disease (4 items), Cognitive function (6 items), Work status (4 items), Sexual function (4 items), Quality of social interaction (4 items), and Sleep (9 items). Also included are three additional quality of life scales: Social support (4 items), Dialysis staff encouragement (6 items), and Patient satisfaction (2 items).

The symptom/problem list assesses the extent of bother (*Not at All, Somewhat, Moderately, Very Much, Extremely*) during the last 30 days in terms of issues particularly relevant to patients with kidney disease including soreness in muscles, pain (joint, back, chest), headaches, cramps during dialysis, bruising, itchy skin, shortness of breath, dizziness, lack of appetite, excessive thirst, numbness in hands or feet, trouble with memory, blurred vision, nausea, and clotting or other problems with the access site. Effects of kidney disease on daily life were assessed using the same five-point response scale used for the symptom/problem list and included restrictions on fluid and dietary intake, and impact on work, carrying out family responsibilities, travel, lifting objects, personal appearance, and time available to get things done. The burden of kidney disease scale assesses perceptions of frustration and interference of kidney disease in one's life using a definitely true to definitely false response scale (interferes too much with life, too much time spent dealing with it, feel frustrated dealing with it, feel like a burden on family).

Work status is measured in terms of whether each person was able to work full- or part-time, was working, and the number of months worked for pay in the past 12 months. The cognitive function items are indicators of impaired-thinking derived from the SIP (Bergner et al., 1981; Stewart et al., 1992). Adopted directly into the questionnaire were: the quality of social interaction scale from the Functional Status Questionnaire

(Jette et al., 1986), the MOS sexual function scale (Sherbourne, 1992), the SIP sleep subscale (Bergner et al., 1981), and a social support scale previously developed (Devinsky et al., 1995). Six items were written de novo for this study to assess the extent to which dialysis staff encourage patients to be independent and lead as normal a life as possible. Patient satisfaction was evaluated using two items culled from existing measures (Coulter, Hays, & Danielson, 1994; Marshall & Hays, 1994).

To help select the KDQOL-SF™ items, the KDQOL™ scale scores were regressed on the items composing them and Goodnight's maximum R-squared improvement procedure was employed to select a subset of items (Hocking, 1976). The Goodnight procedure uses a forward selection process to test the effects of switching different pairs of variables on the total amount of variance explained, starting by finding the one variable that produces the largest R-squared value. Then, controlling for the variable already in the equation, the variable that yields the greatest increase in R-squared is added. This stepwise process was repeated for each scale until enough items were identified to account for approximately 90% of the variance in the long-form scale score.

The stepwise analysis was performed in the overall sample and in two random halves of the sample, but the results of the split sample analysis are not used as the sole basis for item selection because the reduction in sample size due to splitting makes the results somewhat instable. Rather, we use the split samples to provide cross-validated R-squared estimates for the correlation between the KDQOL-SF™ 1.3 and the KDQOL™ long-form scales. Many of the items that were selected based on the overall sample would also be selected from results of both split samples.

The items identified in the regression analysis are listed in Table 1 along with the R-squared values for "predicting" the KDQOL™ scales after adding items sequentially to the model. R-squared values ranging from 0.89 (social support) to 0.95 (burden of kidney disease, quality of social interaction) were obtained for models including from one (patient satisfaction) to six (symptom/problems) items. To enhance content validity, we supplemented these empirically identified items with six additional symptoms (cramps, itchy skin, shortness of breath, lack of appetite, nausea or upset stomach, problems with your access or catheter site), three additional effects of kidney disease (fluid restrictions, dietary restrictions, travel restrictions), one additional burden of kidney disease (too much of my time is spent dealing with my kidney disease), and an item assessing the ability to work full-time.

We modified some of the items selected for the KDQOL-SF™ as a result of feedback from international consultants to the Baxter Renal Outcomes Study (Jordi Alonso, Giovanni Apolone, Monika Bullinger, Shunichi Fukuhara, Alain Leplège). For example, the response scale anchors for item 17 were changed to *Very Bad* and *Very Good*. We also added explanatory material to this sleep item to help respondents answer it. In addition, we replaced the other three sleep items with three items (18a-c) from the MOS sleep scale (Hays & Stewart, 1992). Similarly, we substituted two new dialysis staff encouragement items (24a,b) for the previous items. Finally, the wording of the sexual function items (16a, b) and social support items (19a, b) was improved.

Internal consistency reliability estimates (Cronbach, 1951) for the KDQOL-SF™ scales and correlations of these abbreviated scales with their corresponding KDQOL™ scales

in the two split samples are provided in Table 2.

## SCORING RULES

Precoded numeric values for responses on some of the KDQOL-SF™ items are in the direction such that a higher number reflects a more favorable health state. For example, a response of "None of the time" for item 10 corresponds to a precoded value of "5." However, precoded values for some of the items on the KDQOL-SF™ are in the direction such that a smaller number reflects a more favorable health state. For example, a response of "Not at all" for item 6 is a more favorable state and corresponds to a precoded value of "1."

The scoring procedure for the KDQOL-SF™ first transforms the raw precoded numeric values of items to a 0-100 possible range, with higher transformed scores always reflecting better quality of life. Each item is put on a 0 to 100 range so that the lowest and highest possible scores are set at 0 and 100, respectively. Scores represent the percentage of total possible score achieved. Table 3 provides the recoding necessary for the majority of the KDQOL-SF™ items.

Four of the KDQOL-SF™ items (not listed in Table 3) require additional instructions. Item 17 and 22 need to be multiplied by 10 to put them on a 0-100 possible range. Item 23 is on a 1-7 precoded range. To recode this item, subtract 1 (possible minimum) from the precoded value, divide the difference by 6 (difference between possible maximum and minimum), and then multiply by 100. Item 16 needs to be considered with creating the sexual function scale (see below).

In the second and final step in the scoring process, items in the same scale are averaged together to create the scale scores. Table 4 lists the items averaged together to create each scale. Items that are left blank (missing data) are not taken into account when calculating the scale scores. Hence, scale scores represent the average for all items in the scale that the respondent answered. If the answer to item 16 is "no," the sexual function scale score should be coded as missing.

As shown in Table 5, internal consistency reliability estimates for the KDQOL-SF™ kidney disease-targeted scales exceeded 0.80, with two exceptions (0.68 for cognitive function, 0.61 for quality of social interaction). Mean values for the kidney disease-targeted scales ranged from 25.26 (work status, SD = 37.82) to 79.11 (cognitive function, SD = 19.75) on the percent of total possible (0-100) scores. Reliability estimates for the eight scales of the 36-item health survey were also quite acceptable and ranged from 0.78 to 0.92. Reliability estimates and average scores for the 36-item health survey pain and general health scales were very similar when scored using the RAND (Hays et al., 1993) or SF-36™ (Ware, 1993) scoring algorithms, although the RAND scoring yielded somewhat higher values for the pain scale, as previously noted (Hays et al., 1993, 1994).

## REFERENCES

- Bergner, M., Bobbitt, R. A., Carter, W. B., & Gilson, B. S. (1981). The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care*, *19*, 787-805.
- Coulter, I. D., Hays, R. D., & Danielson, C. (1994). The Chiropractic Satisfaction Questionnaire. *Topics in Clinical Chiropractic*, *1*, 40-43.
- Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, *16*, 297-334.
- Devinsky, O., Vickrey, B. G., Cramer, J., Perrine, K., Hermann, B., Meador, K., & Hays, R. D. (1995). Development of the Quality of Life in Epilepsy (QOLIE) Inventory. *Epilepsia*, *36*, 1089-1104.
- Hays, R. D., Kallich, J. D., Mapes, D. L., Coons, S. J., & Carter, W. B. (1994). Development of the Kidney Disease Quality of Life (KDQOL™) Instrument. *Quality of Life Research*, *3*, 329-338.
- Hays, R. D., Sherbourne, C. D., & Mazel, R. M. (1993). The RAND 36-Item Health Survey 1.0. *Health Economics*, *2*, 217-227.
- Hays, R. D., & Stewart, A. L. (1992). Sleep measures. In A. L. Stewart & J. E. Ware (eds.), *Measuring functioning and well-being: The Medical Outcomes Study approach* (pp. 235-259), Durham, NC: Duke University Press.
- Hocking, R. R. (1976). The analysis and selection of variables in linear regression. *Biometrics*, *32*, 1-50.
- Jette, A. M., Davies, A. R., Cleary, P. D., Calkins, D. R., Rubenstein, L. V., Fink, A., Kosecoff, J., Young, R. T., Brook, R. H., & Delbanco, T. L. (1986). The functional status questionnaire: Reliability and validity when used in primary care. *Journal of General Internal Medicine*, *1*, 143-149.
- Krueger, R. A. (1988). *Focus groups: A practical guide for applied research*. Newbury Park: Sage.
- Kurtin, P. S., Davies, A. R., Meyer, K. B., DeGiacomo, J. M., & Kantz, M. E. (1992). Patient-based health status measures in outpatient dialysis: Early experiences in developing an outcomes assessment program. *Medical Care*, *30*, MS136-MS149.
- Kurtin, P., & Nissenson, A. R. (1993). Variation in end-stage renal disease patient outcomes: What we know, what should we know, and how do we find it out? *Journal of the American Society of Nephrology*, *3*, 1738-1747.
- Kutner, N. G., Brogan, D., & Kutner, M. H. (1986). End-stage renal disease treatment modality and patients' quality of life. *American Journal of Nephrology*, *6*, 396-402.
- Laupacis, A., Wong, C., Churchill, D., and the Canadian Erythropoietin Study Group. (1991). The use of generic and specific quality-of-life measures in hemodialysis patients treated with erythropoietin. *Controlled Clinical Trials*, *12*, 168s-179s.
- Levin, N. W., Lazarus, J. M., & Nissenson, A. R. (1993). Maximizing patient benefits with epoetin alfa therapy: National cooperative rHu erythropoietin study in patients with chronic renal failure--An interim report. *American Journal of Kidney Diseases*, *22*, 3-12.
- Marshall, G. N., & Hays, R. D. (1994). *The Patient Satisfaction Questionnaire Short-Form (PSQ-18)*. Santa Monica, Ca: RAND, P-7865.
- Sherbourne, C. D. (1992). Social functioning: Sexual problems measures. In A. L. Stewart & J. E. Ware (eds.), *Measuring functioning and well-being: The Medical Outcomes Study approach* (pp. 194-204), Durham, NC: Duke University Press.



- Stewart, A. L., Ware, J. E., Sherbourne, C. D., & Wells, K. B. (1992). Psychological distress/well-being and cognitive functioning measures. In A. L. Stewart & J. E. Ware (eds.), *Measuring functioning and well-being: The Medical Outcomes Study approach* (pp. 102-142), Durham, NC: Duke University Press.
- Ware, J.E., & Sherbourne, C.D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical Care, 30*, 473-483.
- Whittington, R., Barradell, L. B., & Benfield, P. (1993). Epoetin: A pharmacoeconomic review of its use in chronic renal failure and its effects on quality of life. *PharmacoEconomics, 3*, 45-82.

**Table 1: Regression of KDQOL™ scales on items**

Scale (Item)	Incremental R-squared
<b><u>Symptoms</u></b>	
1. Washed out or drained .....	.60
2. Soreness in your muscles .....	.75
3. Faintness or dizziness .....	.83
4. Numbness in hands or feet.....	.87
5. Chest pain .....	.89
6. Dry skin .....	<b>.91</b>
<b><u>Effects of kidney disease</u></b>	
7. Stress or worries caused by kidney disease .....	.65
8. Work around the house .....	.81
9. Your sex life .....	.86
10. Being dependent on doctors and other medical staff.....	<b>.90</b>
<b><u>Burden of kidney disease</u></b>	
11. I feel frustrated dealing with my kidney disease .....	.71
12. My kidney disease interferes too much with my life.....	.87
13. I feel like a burden on my family.....	<b>.95</b>
<b><u>Work status</u></b>	
14. Working full-time or part-time during last 30 days .....	.83
15. Are you now able to work part-time? .....	<b>.94</b>
<b><u>Cognitive function</u></b>	
16. Difficulty doing activities involving concentration and thinking .....	.69
17. Become confused and start several activities at a time.....	.83
18. React slowly to things that were said or done .....	<b>.92</b>
<b><u>Quality of social interaction</u></b>	
19. Act irritable toward those around you .....	.71
20. Isolate yourself from people around you .....	.87
21. Get along well with other people.....	<b>.95</b>
<b><u>Sexual function</u></b>	
22. Inability to relax and enjoy sex.....	.86
23. Difficulty in becoming sexually aroused .....	<b>.95</b>

**Table 1 (continued)**

---

<b>Scale (Item)</b>	<b>Incremental R-squared</b>
<b><i>Sleep</i></b>	
24. 0 to 10 self-rating of quality of sleep in last 30 days .....	.62
25. Lie down more often during the day in order to rest .....	.80
26. Sleep or nap more during the day .....	.86
27. Sleep less at night .....	<b>.90</b>
<b><i>Social support</i></b>	
28. Support and understanding from family and friends .....	.77
29. Amount of togetherness with family and friends .....	<b>.89</b>
<b><i>Dialysis staff encouragement</i></b>	
30. Dialysis staff counsel about achieving full potential .....	.74
31. Dialysis staff encourage patients to lead normal life .....	<b>.90</b>
<b><i>Patient satisfaction</i></b>	
32. Friendliness and interest shown in you as a person .....	<b>.91</b>

---

**Table 2: Internal consistency reliability and correlations of KDQOL-SF™ scales with KDQOL™ scales**

Scale	Number of Items	Internal Consistency Reliability	Correlation with KDQOL™ Long-Form	
			(A)	(B)
Symptoms	12	0.84	0.96	0.91
Effects of kidney disease	8	0.82	0.95	0.91
Burden of kidney disease	4	0.83	1.00+	1.00+
Work status	2	0.83	0.99	0.98
Cognitive function	3	0.68	0.95	0.93
Quality of social interaction	3	0.61	0.97	0.98
Sexual function	2	0.89	0.98	0.97
Sleep	4	0.90	0.91	0.91
Social support	2	0.89	0.94	0.94
Dialysis staff encouragement	2	0.90	0.96	0.94
Patient satisfaction	1	NA	0.96	0.95

**Note:** (A) first random half of the sample (n=92); (B) second random half of the sample (n=73); NA = not applicable for single-item measure. + = short- and long-form scale is the same.

**Table 3: Step 1-- Recoding Items**

ITEM NUMBERS	Original response category [a]	To recoded value of
4a-d, 5a-c, 21	1 ----- >	0
	2 ----- >	100
3a-j	1 ----- >	0
	2 ----- >	50
	3 ----- >	100
19a, b	1 ----- >	0
	2 ----- >	33.33
	3 ----- >	66.66
	4 ----- >	100
10, 11a, c, 12a-d	1 ----- >	0
	2 ----- >	25
	3 ----- >	50
	4 ----- >	75
	5 ----- >	100
9b, c, f, g, i, 13e 18b	1 ----- >	0
	2 ----- >	20
	3 ----- >	40
	4 ----- >	60
	5 ----- >	80
	6 ----- >	100
20	1 ----- >	100
	2 ----- >	0
1-2, 6, 8, 11b,d, 14a-m, 15a-h, 16a-b, 24a-b	1 ----- >	100
	2 ----- >	75
	3 ----- >	50
	4 ----- >	25
	5 ----- >	0
7, 9a, d, e, h, 13a-d,f 18a,c	1 ----- >	100
	2 ----- >	80
	3 ----- >	60
	4 ----- >	40
	5 ----- >	20
	6 ----- >	0

**Note:** Item 1 and items 7-8 are scored slightly differently by investigators from the New England Medical Center (c.f. Hays et al., 1993). Four of the KDQOL-SF™ items not listed in this table (items 16,17,22,23) require additional instructions (see page 5).

**Table 4: Step 2--Averaging Items to Form Scales**

Scale	Number of Items	After Recoding Per Table 3, Average the Following Items
<b><i>ESRD-targeted Areas</i></b>		
Symptom/problem list	12	14a-k, l (m)*
Effects of kidney disease	8	15a-h
Burden of kidney disease	4	12a-d
Work status	2	20, 21
Cognitive function	3	13b, d, f
Quality of social interaction	3	13a, c, e
Sexual function	2	16a, b
Sleep	4	17, 18a-c
Social support	2	19a, b
Dialysis staff encouragement	2	24a, b
Patient satisfaction	1	23
<b><i>36-item health survey (SF-36)</i></b>		
Physical functioning	10	3a-j
Role--physical	4	4a-d
Pain	2	7, 8
General health	5	1, 11a-d
Emotional well-being	5	9b, c, d, f, h
Role--emotional	3	5a-c
Social function	2	6, 10
Energy/fatigue	4	9a, e, g, i

**Note:** The SF-36 change in health and the 0-10 overall health rating items are scored as single items.

\* 14l is answered by those on hemodialysis; 14m is answered by those on peritoneal dialysis

**Table 5: Central tendency, variability (including floor and ceiling effects), and reliability of KDQOL-SF™ scales**

Measure	Mean	Standard Deviation	% Floor	% Ceiling	Internal Consistency Reliability
<b><i>Kidney disease-targeted scales</i></b>					
Symptom/problems	71.21	16.77	0.0	1.2	0.84
Effects of kidney disease	57.30	24.53	0.6	5.0	0.82
Burden of kidney disease	49.62	30.27	6.1	8.0	0.83
Work status	25.26	37.82	63.5	16.4	0.83
Cognitive function	79.11	19.75	0.0	21.3	0.68
Quality of social interaction	76.65	18.71	0.0	15.9	0.61
Sexual function	69.30	36.17	11.6	44.9	0.89
Sleep	60.68	28.61	0.0	7.5	0.90
Social support	64.61	27.73	3.1	16.9	0.89
Dialysis staff encouragement	69.90	23.13	1.3	19.1	0.90
Patient satisfaction	71.38	22.04	0.6	22.0	NA
<b><i>36-Item Health Survey scales*</i></b>					
Physical functioning	51.83	29.73	3.6	3.6	0.92
Role--physical	32.46	39.68	49.4	20.4	0.87
Pain					
RAND scoring	60.40	30.11	3.1	20.2	0.87
SF-36™ scoring	57.60	29.70	3.1	20.2	0.90**
General health perceptions					
RAND scoring	42.88	24.32	3.0	1.8	0.78
SF-36™ scoring	43.87	24.75	3.0	1.8	0.78
Emotional well-being	69.54	20.36	0.6	4.3	0.80
Role--emotional	57.76	43.90	29.2	47.2	0.86
Social function	63.57	29.77	4.3	25.0	0.87
Energy/fatigue	45.89	24.06	2.4	1.2	0.90
<b><i>Overall health rating</i></b>	<b>59.37</b>	<b>19.54</b>	<b>0.6</b>	<b>5.0</b>	<b>NA</b>

**Note:** Feedback from international consultants to the Baxter Renal Outcomes Study lead to modifications to the sleep, dialysis staff encouragement, sexual function, cognitive function, and social support items. Results presented here do not reflect these modifications.

\* - Also includes one item assessing change in health.

\*\* - Internal consistency reliability estimate is inflated because scoring of one of the items is conditional on the value of the other. Differences in RAND and SF-36 scoring of pain and general health perception scores are discussed elsewhere (Hays et al, 1993).

NA - Not applicable for a single-item measure.

**APPENDIX**

**KIDNEY DISEASE AND QUALITY OF LIFE  
SHORT FORM QUESTIONNAIRE**

**(KDQOL-SF™)**



# KIDNEY DISEASE AND QUALITY OF LIFE SHORT FORM

(KDQOL - SF™)

## Administration Instructions for Version 1.3

The Kidney Disease and Quality of Life questionnaire is written as a self-administered survey. To facilitate administration of the survey during a dialysis session, we recommend that the survey be put into a one-inch three-ring binder. This allows the patient to place the instrument on his/her lap and fill it out with one hand. It will take a patient approximately 20-30 minutes to fill out the survey. Whenever possible, patients should complete the questionnaire on their own. Some patients--for various reasons--will be unable to complete the survey without assistance. Please follow these rules when using this questionnaire as an interviewer-administered survey.

### **Read the Entire Question**

Respondents, that is patients answering the questions you read, may interrupt you with an answer before you have read a question in full. It is very important that the respondent hear the whole question (including information in parentheses), before giving a response. So, always read the question in full.

### **Read the Answer Choices**

For most questions you will need to read the full list of answer choices to the respondent, allowing him or her to pick the one answer that best captures his or her information or response. It is important that the respondent hears all the answer choices before giving a response. If the respondent interrupts you, keep reading until you have reached the end of the list.

Some questions ask about a series of statements, symptoms, or conditions and use the same answer choices over and over. If the respondent is visually impaired or otherwise cannot read, repeat the answer choices every fourth item or so.

### **Probing an Unclear Response**

Sometimes a respondent will give you an answer that fits into more than one answer choice. If the question includes the instruction "(Circle One Number)," the respondent must choose just one answer. For example, when you ask question 1:

"In general, would you say your health is: excellent, very good, good, fair, or poor?"

And the respondent says:

"Pretty good."

To this person, "pretty good" might be the same as "very good" or it might mean "good." You need to **probe in a neutral, non-directive manner** to find out which answer choice best captures how this person feels about his or her health. A good probe in this case is: "Would you say very good or good?" Or you could repeat the full list of answer choices. As long as you give the respondent a choice between (at least) two answers, you are probing in a neutral way that will not influence which answer he or she chooses. This will insure that the data you collect is reliable and valid.

As a general rule, probe whenever a respondent's answer is vague or does not clearly fit the answer choices available.

### Notes or Comments

Please feel free to make notes or comments in the questionnaire margin if you want to give us extra information that will help us understand a respondent's answer (for example, if the respondent is in a wheelchair) or if the respondent had a comment or concern about a question.

### Taking the Survey Home

If a patient asks to take the survey home to complete, please read the following instructions to the patient:

Please complete the survey yourself -- do not have someone else help you complete it. If you want assistance, we have staff here who are trained to help you so that your answers will be as accurate as possible. If you decide to take the survey home, please fill it out in one sitting and in private. Please complete and return the survey within 5 days. Do you understand these instructions?

If, after reading these instructions, the patient still wants to take the survey home, please do the following:

1. Print on the front of the survey:
  - a) Date taken home:      \_\_\_\_\_      \_\_\_\_\_      \_\_\_\_\_  
    Month                      Day                      Year
  - b) Date returned:        \_\_\_\_\_      \_\_\_\_\_      \_\_\_\_\_  
    Month                      Day                      Year
2. Write in your calendar or date book "KDQOL" and then the patient's name on the next scheduled dialysis day or two days from today, whichever is sooner.
3. Ask the patient at their next scheduled dialysis day, or two days from today, for the survey.
4. If the patient did not bring the survey back, please continue to follow-up with the patient to get the survey completed and returned.
5. Fill in the return date on the front of the questionnaire.

# **KIDNEY DISEASE AND QUALITY OF LIFE™**

**SHORT FORM**

**(KDQOL-SF™)**

**VERSION 1.3**

**Patient Study Number: \_\_\_\_\_**

**RAND  
1700 Main Street  
Santa Monica, California 90407-2138  
(310) 393-0411**

## **STUDY OF QUALITY OF LIFE FOR PATIENTS ON DIALYSIS**

### **WHAT IS THE PURPOSE OF THE STUDY?**

This study is being carried out in cooperation with physicians and their patients. The purpose is to assess the quality of life of patients with kidney disease.

### **WHAT WILL I BE ASKED TO DO?**

For this study, we want you to complete a survey today about your health, how you feel and your background.

### **CONFIDENTIALITY OF INFORMATION?**

We do not ask for your name. Your answers will be combined with those of other participants in reporting the findings of the study. Any information that would permit identification of you will be regarded as strictly confidential. In addition, all information collected will be used only for purposes of the study, and will not be disclosed or released for any other purpose without your prior consent.

### **HOW WILL PARTICIPATION BENEFIT ME?**

The information you provide will tell us how you feel about your care and further understanding about the effects of medical care on the health of patients. This information will help to evaluate the care delivered.

### **DO I HAVE TO TAKE PART?**

You do not have to fill out the survey and you can refuse to answer any question. Your decision to participate will not affect your opportunity to receive care.

**INSTRUCTIONS FOR FILLING OUT SURVEY**

- A. This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.
- B. This survey includes a wide variety of questions about your health and your life. We are interested in how you feel about each of these issues.
- C. Please answer the questions by circling the appropriate number or by filling in the answer as requested.

Example:

During the past four weeks, how much back pain have you had?

(Circle One Number)

- None ..... ①
- Very mild ..... 2
- Mild ..... 3
- Moderate ..... 4
- Severe ..... 5

- D. Several items in the survey ask about the effect of kidney disease on your life. Some items will ask about limitations related to your kidney disease, and some items will ask about your well-being. Some questions may look like others, but each one is different. Please answer every question as honestly as possible. If you are unsure about how to answer a question, please give the best answer you can. This will allow us to have an accurate picture of the different experiences of individuals with kidney disease.

**THANK YOU FOR COMPLETING THIS SURVEY**

**YOUR HEALTH**

1. In general, would you say your health is:

**(Circle One Number)**

- Excellent ..... 1
- Very good ..... 2
- Good ..... 3
- Fair ..... 4
- Poor ..... 5

2. **Compared to one year ago**, how would you rate your health in general **now**?

**(Circle One Number)**

- Much better now than one year ago ..... 1
- Somewhat better now than one year ago ..... 2
- About the same as one year ago ..... 3
- Somewhat worse now than one year ago ..... 4
- Much worse now than one year ago ..... 5

3. The following items are about activities you might do during a typical day. **Does your health now limit** you in these activities? If so, how much?

(Circle One Number on Each Line)

	Yes, Limited <u>a Lot</u>	Yes, Limited <u>a Little</u>	No, Not Limited <u>at All</u>
a. <b>Vigorous activities</b> , such as running, lifting heavy objects, participating in strenuous sports ....	1	2	3
b. <b>Moderate activities</b> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf ....	1	2	3
c. Lifting or carrying groceries .....	1	2	3
d. Climbing <b>several</b> flights of stairs ...	1	2	3
e. Climbing <b>one</b> flight of stairs .....	1	2	3
f. Bending, kneeling, or stooping .....	1	2	3
g. Walking <b>more than a mile</b> .....	1	2	3
h. Walking <b>several blocks</b> .....	1	2	3
i. Walking <b>one block</b> .....	1	2	3
j. Bathing or dressing yourself .....	1	2	3

4. During the **past 4 weeks**, have you had any of the following problems with your work or other regular activities **as a result of your physical health?**

(Circle One Number on Each Line)

	<u>Yes</u>	<u>No</u>
a. Cut down the <b>amount of time</b> you spent on work or other activities? .....	1	2
b. <b>Accomplished less</b> than you would have liked?.....	1	2
c. Were limited in the <b>kind</b> of work or other activities?.....	1	2
d. Had <b>difficulty</b> performing the work or other activities (for example, it took extra effort)? .....	1	2

5. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

(Circle One Number on Each Line)

	<u>Yes</u>	<u>No</u>
a. Cut down the <b>amount of time</b> you spent on work or other activities? .....	1	2
b. <b>Accomplished less</b> than you would like? .....	1	2
c. Didn't do work or other activities <b>as carefully as usual?</b> .....	1	2



6. During the **past 4 weeks**, to what **extent** have your **physical health or emotional problems** interfered with your normal social activities with family, friends, neighbors, or groups?

**(Circle One Number)**

- |                   |   |
|-------------------|---|
| Not at all .....  | 1 |
| Slightly .....    | 2 |
| Moderately .....  | 3 |
| Quite a bit ..... | 4 |
| Extremely .....   | 5 |

7. How much **bodily** pain have you had during the **past 4 weeks**?

**(Circle One Number)**

- |                   |   |
|-------------------|---|
| None .....        | 1 |
| Very mild .....   | 2 |
| Mild .....        | 3 |
| Moderate .....    | 4 |
| Severe .....      | 5 |
| Very severe ..... | 6 |

8. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

**(Circle One Number)**

- |                    |   |
|--------------------|---|
| Not at all .....   | 1 |
| A little bit ..... | 2 |
| Moderately .....   | 3 |
| Quite a bit .....  | 4 |
| Extremely .....    | 5 |

9. These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks** . . .

**(Circle One Number on Each Line)**

	<u>All of the Time</u>	<u>Most of the Time</u>	<u>A Good Bit of the Time</u>	<u>Some of the Time</u>	<u>A Little of the Time</u>	<u>None of the Time</u>
a. Did you feel full of pep? .....	1	2	3	4	5	6
b. Have you been a very nervous person? .....	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up? .....	1	2	3	4	5	6
d. Have you felt calm and peaceful? .....	1	2	3	4	5	6
e. Did you have a lot of energy? .....	1	2	3	4	5	6
f. Have you felt downhearted and blue? .....	1	2	3	4	5	6
g. Did you feel worn out? .....	1	2	3	4	5	6
h. Have you been a happy person? .....	1	2	3	4	5	6
i. Did you feel tired? .....	1	2	3	4	5	6

10. During the **past 4 weeks**, how much of the **time** have your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

**(Circle One Number)**

- All of the time ..... 1
- Most of the time ..... 2
- Some of the time ..... 3
- A little of the time ..... 4
- None of the time ..... 5

11. Please choose the answer that best describes how **TRUE** or **FALSE** each of the following statements is for you.

**(Circle One Number on Each Line)**

	<u>Definitely True</u>	<u>Mostly True</u>	<u>Don't Know</u>	<u>Mostly False</u>	<u>Definitely False</u>
a. I seem to get sick a little easier than other people .....	1	2	3	4	5
b. I am as healthy as anybody I know .....	1	2	3	4	5
c. I expect my health to get worse .....	1	2	3	4	5
d. My health is excellent .....	1	2	3	4	5

<b>YOUR KIDNEY DISEASE</b>
----------------------------

12. How **TRUE** or **FALSE** is each of the following statements for you?

**(Circle One Number on Each Line)**

	<u>Definitely True</u>	<u>Mostly True</u>	<u>Don't Know</u>	<u>Mostly False</u>	<u>Definitely False</u>
a. My kidney disease interferes too much with my life .....	1	2	3	4	5
b. Too much of my time is spent dealing with my kidney disease .....	1	2	3	4	5
c. I feel frustrated dealing with my kidney disease .....	1	2	3	4	5
d. I feel like a burden on my family .....	1	2	3	4	5

13. These questions are about how you feel and how things have been going during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks** . . .

**(Circle One Number on Each Line)**

	<u>None of the Time</u>	<u>A Little of the Time</u>	<u>Some of the Time</u>	<u>A Good bit of the Time</u>	<u>Most of the Time</u>	<u>All of the Time</u>
a. Did you isolate yourself from people around you? .....	1	2	3	4	5	6
b. Did you react slowly to things that were said or done? .....	1	2	3	4	5	6
c. Did you act irritable toward those around you? .....	1	2	3	4	5	6
d. Did you have difficulty concentrating or thinking? .....	1	2	3	4	5	6
e. Did you get along well with other people? .....	1	2	3	4	5	6
f. Did you become confused? .....	1	2	3	4	5	6

14. During the **past 4 weeks**, to what extent were you bothered by each of the following?

**(Circle One Number on Each Line)**

	<u>Not at All bothered</u>	<u>Somewhat bothered</u>	<u>Moderately bothered</u>	<u>Very Much bothered</u>	<u>Extremely bothered</u>
a. Soreness in your muscles?.....	1	2	3	4	5
b. Chest pain?.....	1	2	3	4	5
c. Cramps? .....	1	2	3	4	5
d. Itchy skin? .....	1	2	3	4	5
e. Dry skin?.....	1	2	3	4	5
f. Shortness of breath?.....	1	2	3	4	5
g. Faintness or dizziness? .....	1	2	3	4	5
h. Lack of appetite?	1	2	3	4	5
i. Washed out or drained?.....	1	2	3	4	5
j. Numbness in hands or feet?.....	1	2	3	4	5
k. Nausea or upset stomach? .....	1	2	3	4	5

14. (Continued) During the **past 4 weeks**, to what extent were you bothered by each of the following?

**(Circle One Number on Each Line)**

Not at All <u>bothered</u>	Somewhat <u>bothered</u>	Moderately <u>bothered</u>	Very Much <u>bothered</u>	Extremely <u>bothered</u>
----------------------------------	-----------------------------	-------------------------------	---------------------------------	------------------------------

Hemodialysis Patient only

I. Problems with your access site?.....	1	2	3	4	5
--	---	---	---	---	---

Peritoneal Dialysis Patient only

m. Problems with your catheter site?.....	1	2	3	4	5
--	---	---	---	---	---

<b>EFFECTS OF KIDNEY DISEASE ON YOUR DAILY LIFE</b>
---

15. Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease **bother** you in each of the following areas?

**(Circle One Number on Each Line)**

	<u>Not at All bothered</u>	<u>Somewhat bothered</u>	<u>Moderately bothered</u>	<u>Very Much bothered</u>	<u>Extremely bothered</u>
a. Fluid restriction?	1	2	3	4	5
b. Dietary restriction?	1	2	3	4	5
c. Your ability to work around the house?	1	2	3	4	5
d. Your ability to travel? .....	1	2	3	4	5
e. Being dependent on doctors and other medical staff? .....	1	2	3	4	5
f. Stress or worries caused by kidney disease?.....	1	2	3	4	5
g. Your sex life?.....	1	2	3	4	5
h. Your personal appearance? .....	1	2	3	4	5



The next three questions are personal and relate to your sexual activity, but your answers are important in understanding how kidney disease impacts on people's lives.

16. Have you had any sexual activity in the **past 4 weeks**?

(Circle One Number)

No ..... 1  
 Yes ..... 2

Please skip to Question 17



How much of a problem was each of the following in the **past 4 weeks**?

(Circle One Number on Each Line)

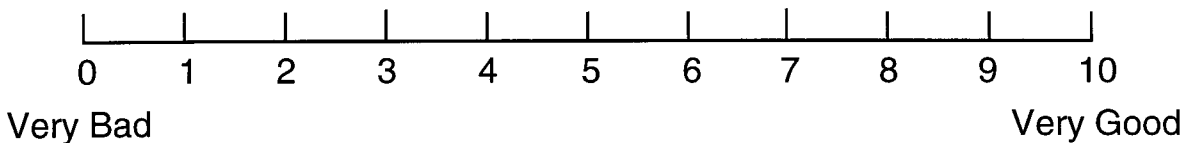
	<u>Not a Problem</u>	<u>A Little Problem</u>	<u>Somewhat of a Problem</u>	<u>Very Much a Problem</u>	<u>Severe Problem</u>
a. Enjoying sex? .....	1	2	3	4	5
b. Becoming sexually aroused? .....	1	2	3	4	5

For the following question, please rate your sleep using a scale ranging from 0 representing "very bad" to 10 representing "very good."

If you think your sleep is half-way between "very bad" and "very good," please circle 5. If you think your sleep is one level better than 5, circle 6. If you think your sleep is one level worse than 5, circle 4 (and so on).

17. On a scale from **0** to **10**, how would you rate your sleep overall?

(Circle One Number)



18. How often during the **past 4 weeks** did you...

**(Circle One Number on Each Line)**

	<u>None of the Time</u>	<u>A Little of the Time</u>	<u>Some of the Time</u>	<u>A Good bit of the Time</u>	<u>Most of the Time</u>	<u>All of the Time</u>
a. Awaken during the night and have trouble falling asleep again? .....	1	2	3	4	5	6
b. Get the amount of sleep you need? .....	1	2	3	4	5	6
c. Have trouble staying awake during the day? .....	1	2	3	4	5	6

19. Concerning your **family and friends**, how satisfied are you with ...

**(Circle One Number on Each Line)**

	<u>Very Dissatisfied</u>	<u>Somewhat Dissatisfied</u>	<u>Somewhat Satisfied</u>	<u>Very Satisfied</u>
a. The amount of time you are able to spend with your family and friends?.....	1	2	3	4
b. The support you receive from your family and friends?.....	1	2	3	4

20. During the **past 4 weeks**, did you work at a paying job?

**(Circle One Number)**

Yes ..... 1

No ..... 2

21. Does your health keep you from working at a paying job?

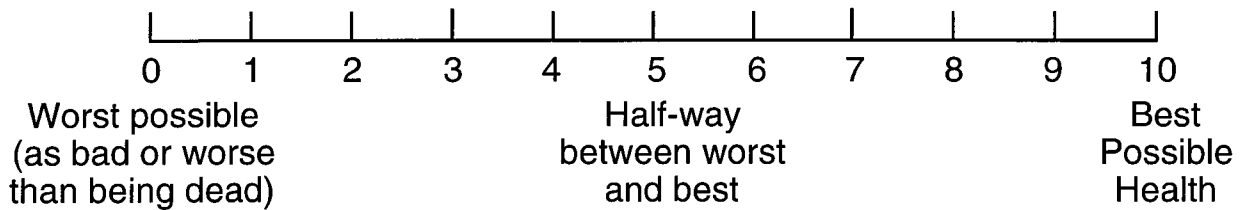
**(Circle One Number)**

Yes ..... 1

No ..... 2

22. Overall, how would you rate your health?

**(Circle One Number)**



**SATISFACTION WITH CARE**

23. Think about the care you receive for kidney dialysis. In terms of your satisfaction, how would you rate the friendliness and interest shown in you as a person?

**(Circle One Number)**

- Very Poor ..... 1
- Poor ..... 2
- Fair ..... 3
- Good ..... 4
- Very Good ..... 5
- Excellent ..... 6
- The Best ..... 7

24. How **TRUE** or **FALSE** is each of the following statements?

**(Circle One Number on Each Line)**

Definitely    Mostly    Don't    Mostly    Definitely  
True        True        Know       False       False

- a. Dialysis staff encourage me to be as independent as possible ..... 1        2        3        4        5
- b. Dialysis staff support me in coping with my kidney disease ..... 1        2        3        4        5

**BACKGROUND INFORMATION**

25. Do you currently take prescription medications regularly (4 or more days a week) that are prescribed by your doctor for a medical condition? Please don't count over the counter medications like antacids or aspirin.

**(Circle One Number)**

No ..... 1 --->

Please skip to Question 26

Yes ..... 2



25a. How many different prescription medications do you currently take?

Number of Medications: \_\_\_\_\_

26. How many days total in the **last 6 months** did you stay in any hospital overnight or longer? **(If none, please write in 0)**

Number of Days: \_\_\_\_\_

27. How many days total in the **last 6 months** did you receive care at a hospital, but came home the same day? **(If none, please write in 0)**

Number of Days: \_\_\_\_\_

28. What caused your kidney disease?

**(Circle All That Apply)**

- Don't know ..... 1
- Hypertension (High Blood Pressure) ..... 2
- Diabetes ..... 3
- Polycystic Kidney Disease ..... 4
- Chronic Glomerulonephritis ..... 5
- Chronic Pyelonephritis ..... 6
- Other (please specify): \_\_\_\_\_ 7
- \_\_\_\_\_

29. When were you born?

--	--

 / 

--	--

 / 

--	--

  
Month                      Day                      Year

30. What is the highest level of school you have completed?

**(Circle One Number)**

- 8th grade or less ..... 1
- Some high school or less ..... 2
- High school diploma or GED..... 3
- Vocational school or some college ..... 4
- College degree ..... 5
- Professional or graduate degree ..... 6

31. What is your gender?

**(Circle One Number)**

- Male ..... 1
- Female ..... 2

32. How do you describe yourself?

**(Circle One Number)**

- African American or Black ..... 1
- Hispanic or Latino ..... 2
- Native American or American Indian ..... 3
- Asian or Pacific Islander ..... 4
- White ..... 5
- Other (please specify): \_\_\_\_\_ 6
- \_\_\_\_\_

33. Are you currently married?

**(Circle One Number)**

- No ..... 1
- Yes ..... 2

34. During the **last 30 days**, were you:

**(Circle One Number)**

- |  |   |
|--|---|
| Working full-time.....                         | 1 |
| Working part-time.....                         | 2 |
| Unemployed, laid off, or looking for work..... | 3 |
| Retired.....                                   | 4 |
| Disabled.....                                  | 5 |
| In school.....                                 | 6 |
| Keeping house.....                             | 7 |
| None of the above.....                         | 8 |

35. What kind of health insurance do you have?

**(Circle One Number)**

- |   |   |
|---|---|
| None, I have no health insurance .....  | 1 |
| Medicare only .....   | 2 |
| Medicare and any other insurance .....  | 3 |
| Medicaid or Medi-Cal only .....   | 4 |
| Private, fee-for-service health insurance (e.g., Prudential, Aetna, etc.) ..... | 5 |
| HMO, PPO, IPA or other prepaid plan (e.g., Kaiser, Cigna, FHP, etc.) .....      | 6 |
| Other (please specify)  | 7 |

---

---



36. What was your total household income (from all sources) before taxes in the **LAST CALENDAR YEAR**, including yourself, your partner, and others you regard as family who live in your household? (Please remember your answers are confidential.)

**(Circle One Number)**

- Less than \$5,000 ..... 1
- \$5,001-\$10,000 ..... 2
- \$10,001-\$20,000 ..... 3
- \$20,001-\$40,000 ..... 4
- \$40,001-\$75,000 ..... 5
- More than \$75,000 ..... 6
- Don't know ..... 7

37. Did someone help you fill out this survey?

**(Circle One Number)**

- Yes, a physician or other health care provider ..... 1
- Yes, a family member or friend ..... 2
- Yes, someone else ..... 3
- No ..... 4

38. What is today's date?

/   /    
 Month Day Year

**THANK YOU FOR TAKING PART IN THIS STUDY.**



RAND/P-7994

Kidney Disease Quality of Life Short Form (KDQOL-SF<sup>™</sup>), Version 1.3:  
A Manual for Use and Scoring

Hays et al.