

Improving Dialysis Patient Health-Related Quality of Life: A Practical Discussion on the Use of the KDQOL 36

December 10, 2008 1 p.m. to 3 p.m. EST (10 a.m. - noon PST)



Housekeeping

- No CEU's for this webinar
- We will take questions at the end
- Download KDQOL Questions and Answers www.kidney.org/professionals/cnsw/pdf/KDQOL_QandA-Webinar11-18-08.pdf
- Email any further questions or comments to

browne@sc.edu

or

aherold@nw16.esrd.net





Disclaimers

Information provided by CNSW is **not** intended to establish or replace policies and procedures provided by dialysis providers to their facilities.

Please check with your dialysis facility management before implementing any information provided here.





Speaker Introductions

- Teri Browne, MSW, PhD: Chair, CNSW
- Dori Schatell, MS: Executive Director, Medical Education Institute; Director, Life Options program
- Ron Hays, Ph.D. (UCLA): Co-developer of KDQOL
- Beth Witten, MSW, ACSW, LSCSW: NKF Medicare Modernization Program Manager detailed to CMS Survey & Certification Group under IPA appointment, Witten and Associates, LLC
- Stephanie Johnstone, LCSW: FMCNA Regional Lead Social Worker, San Diego





Panelists for Q&A

- Aaron Herold, LICSW: Patient Services Coordinator, Northwest Renal Network
- Wendy Funk Schrag, LMSW, ACSW: FMCNA Director of Advocacy & State Government Affairs
- Karen Spritzer: UCLA School of Medicine, KDQOL Working Group
- Virginia Winn, MSW: American Renal Associates Nephrology Social Worker





Why Are We Talking About Using the KDQOL?

CMS Dialysis Conditions for Coverage Condition 494.90 Patient Plan of Care

- (a) Standard: Development of patient plan of care: The interdisciplinary team must develop a plan of care for each patient. The plan of care must address, but not be limited to, the following:
- (6) Psychosocial status. The interdisciplinary team must provide the necessary monitoring and social work interventions. These include counseling services and referrals for other social services, to assist the patient in achieving and sustaining an appropriate psychosocial status as measured by a standardized mental and physical assessment tool chosen by the social worker, at regular intervals, or more frequently on an as-needed basis.

The KDQOL is required by CMS Clinical Performance Measures







Medical Education Institute KDQOL-36 Tools: Today & Tomorrow

Dori Schatell, MS

Medical Education Institute



What HRQOL Isn't







What HRQOL Is

- Patient's perceived mental health
- Patient's perceived physical health
- How a chronic disease interferes with dayto-day life¹

¹CDC - www.cdc.gov/hrqol/index.htm





ESRD Clinical Performance Measures (CPMs) Before 2008

- Adequacy of dialysis (toxins from blood)
- Access to blood (vascular or PD)
- Anemia (red cells in blood)
- Pressure (of blood)
- Electrolytes (in blood)







New ESRD CPM as of 4/1/08

- Percent of patients who take the KDQOL-36 at least once per year
- Exclusions:
 - Age <18</p>
 - Cognitive impairment, dementia, psychosis
 - Non-English speakers/readers (no translations)
 - <3 months on dialysis</p>
 - Patients who refuse





PCS & MCS Scores *Predict*Morbidity & Mortality¹

1 Point in MCS

- **♦• RR** mortality **♦** 2%
- **♦RR hosp. ¥** 1%

1 Point in PCS

- **♦ RR** mortality **4** 2%
- **♦RR hosp. 4** 2%



¹Lowrie EG et al. Medical Outcomes Study Short Form-36: A consistent and powerful predictor of morbidity and mortality in dialysis patients. *Am J Kidney Dis* 41(6):1286-92, 2003.





Some Interventions That Improve Scores (Research-Based)

- APD vs. CAPD¹
- ❖ More frequent HD^{2,3}
- ❖ IV iron & ESAs⁴
- ❖ Bone mineral balance⁵

- Reaching ideal weight⁶
- Adaptation training⁷
- Group counseling⁸
- Exercise training⁹

¹Bro S et al. *Perit Dial Int*. 1999 Nov-Dec;19(6):526-33

²Heidenheim AP et al. Am J Kidney Dis. 2003 Jul;42(1 Suppl):36-41.

³Ting GO et al. Am J Kidney Dis. 2003 Nov;42(5):1020-35.

⁴Agarwal R et al. *Am J Nephrol*. 2006;26(5):445-54

⁵Cunningham J et al. *Kidney Int*. 2005 Oct;68(4):1793-800

⁶Chang ST et al. Nephron Clin Pract. 2004;97(3):c90-7

⁷Tsay SL et al. *J Adv Nurs*. 2005 Apr;50(1):39-46

⁸Lii YC et al. *J Clin Nurs*. 2007 Nov;16(11C):268-75

⁹Painter P et al. Am J Kidney Dis. 2000 Sep;36(3):600-8





- Purpose: Bring renal community up to speed
 - Take the survey & see the items
 - Learn about the subscales
 - See the research-based interpretation
- How to use it:
 - Take the tool yourself (pretend you're a patient)
 - Let web-savvy patients take it





KDQOL™-36 ONLINE

Why Should I Take the KDQOL™-36?

The KDQOL™-36 survey lets you rate your quality of life with kidney disease. Hundreds of studies have found that how you view your physical and mental function is vital. People who had a poor view of their lives were more likely to need hospital care and less likely to live a long time.

You are the only one who can tell us how you feel about your life.

In fact, how you rate your quality of life is one of the best ways to know how you are doing. The Dialysis Outcomes and Practice Patterns Study (DOPPS) looks at people who are on dialysis around the world. The DOPPS found a strong link between how people feel, their quality of life, and how well they do on dialysis.

We ask you to take this survey so you can share things that may affect how well you feel while you receive dialysis treatment. At the end of the survey, we will provide a report that will tell you information about:

- · Your scores on each of 5 subtests
- . How your scores compare to others like you with regard to age, sex, and diabetic status
- · Things you can do to improve your scores

Over time, tracking your scores will help you learn how taking care of yourself affects how you feel.

Help us to help you feel your best with kidney failure.

Ready? Let's begin!

Continue

Professionals: Download accompanying documentation | Send us feedback | KDQOL Website

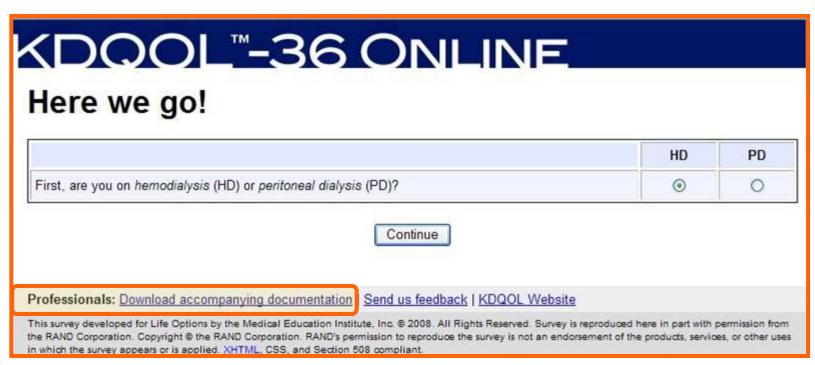
This survey developed for Life Options by the Medical Education Institute, Inc. © 2008. All Rights Reserved. Survey is reproduced here in part with permission from the RAND Corporation. Copyright © the RAND Corporation. RAND corporation. Power is an endorsement of the products, services, or other uses in which the survey appears or is applied. https://linear.pubm.nc.nd/. AND Corporation. Copyright © the products, services, or other uses in which the survey appears or is applied. https://linear.pubm.nc.nd/. AND Corporation.

http://www.lifeoptions.org/kdqol





- ❖ What it *won't* do:
 - Store personal health information
 - Compare scores of multiple patients from a clinic







Results & interpretation

KDQOL"-36 ONLINE

Your Results

Thank you for completing this survey. Your results are posted below, according to the answers you provided. You may print these recommendations for your reference.

PCS

What is a PCS Score?

Your physical component summary (PCS) score reports how you feel about your physical health. In the survey, you were asked if you could do things like climb stairs, move a table, or push a vacuum. How well you think you feel physically is a key measure of your health. PCS scores have been studied in tens of thousands of people on dialysis. When all other things were equal, the PCS score predicted who would not need hospital care, and who was likely to live longer.

Your PCS score is 53.5.

The average PCS score for others on dialysis in the U.S. who are female, about your age, and don't have diabetes is 37. Your score means you may be less likely to need hospital care than those with lower scores. It also means you may live longer.

Try these things to keep feeling your best:

- Stay active. Do chores, work in your garden, walk instead of driving. Even grocery shopping can help you stay fit. If
 you like Tai Chi, yoga, bowling, or soccer, go for it (with your doctor's okay).
- Keep up the good work if you have been doing sports or exercise! Research shows that exercise can lift your
 mood, build your muscles, help your balance, and aid endurance. People on dialysis can safely do most types of
 exercise—talk with your doctor to be sure.





Coming Next Spring: KDQOL-COMPLETE

- Facility-level KDQOL-36 scoring tool
- Online tutorial
- Enter & track all facility patients
- Report by patient or facility
- Array scores for QI purposes
- Report data for CPM
- Spanish translation







Description of the KDQOLTM

Ron D Hays, PhD

<u>drhays@ucla.edu</u>

http://gim.med.ucla.edu/kdqol/



KDQOL Development

- Focus groups with patients and staff
- Pretests on small samples
- Field test with 165 persons with kidney disease at 9 dialysis centers
- Thousands of administrations since





KDQOL[™] Scales

- Symptoms/problems (34, 12)
- Effects of kidney disease (20, 8)
- Burden of kidney disease (4, 4)
- Work status (4, 2)
- Cognitive function (6, 3)
- Quality of social interaction (4, 3)
- Sexual function (4, 2)
- ❖ Sleep (9, 4)
- Social support (4, 2)
- Dialysis staff encouragement (6, 2)
- Patient satisfaction (2, 1)





KDQOL-36

- **❖Items 1-12**: SF-12
- Items 13-16: Burden of Kidney Disease
- Items 17-28: Symptoms/Problems
- Items 29-36: Effects of Kidney Disease





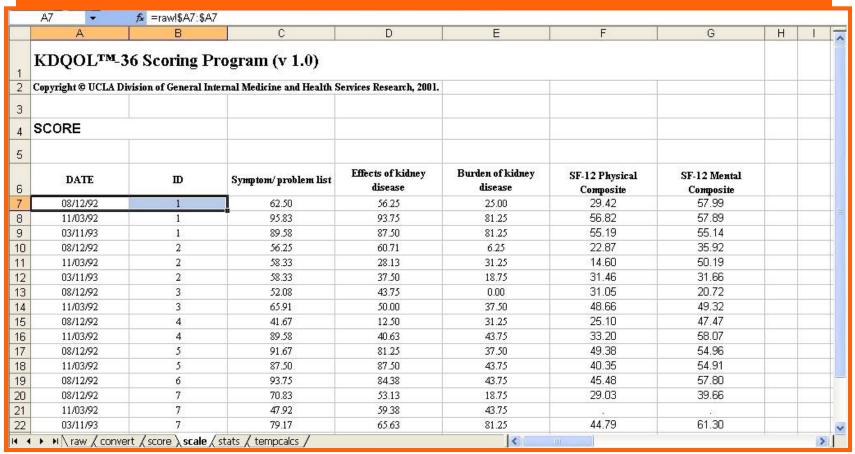
Scoring

- Scoring: higher score = better health
- Transform linearly to 0-100 range
- Average items in each scale together





KDQOL-36 Sample Scoring Template

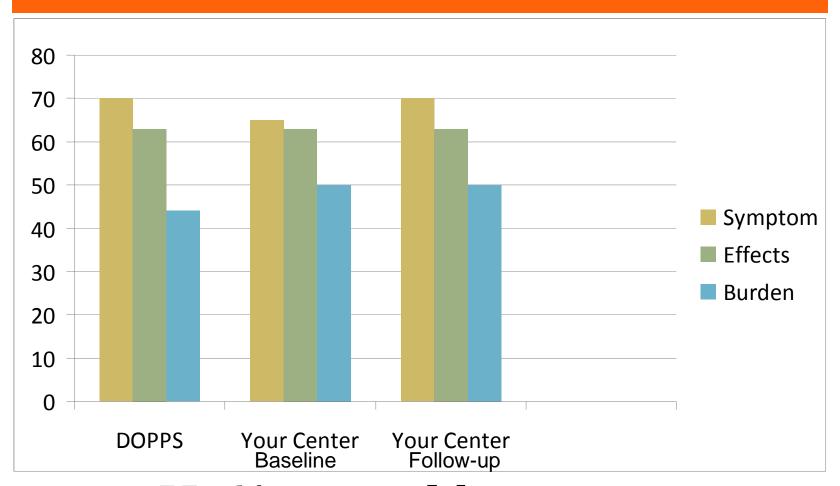


http://gim.med.ucla.edu/kdqol (register for downloads)





Use of KDQOLTM Scores



DOPPS 55-64 year old age group





Thank You!









KDQOL-36: Professional Resources

Beth Witten, MSW, ACSW, LSCSW

National Kidney Foundation, Inc. Witten and Associates, LLC



CNSW's Quality of Life Assessment Tools Fact Sheet



Council of Nephrology Social Workers

Quality of Life Assessment Tools

The Council of Nephrology Social Workers (CNSW) has summarized below the various sources of information regarding the new Conditions for Coverage requirement for a "standardized mental and physical assessment tool," The sources ofted include: the specific standard in the Conditions for Coverage for End-stage Renal Disease Facilities published April 15, 2008, CMS preamble comments regarding the standardized assessment, and the newly released Clinical Performance Measures (CPM). Dialysis facilities are encouraged to reference all three sources of information in order to effectively implement or adjust their use of a standardized assessment. The document also includes a reference to an online tool being development by the Medical Education Institute, Inc. (MELIO), Ideo Options.

Conditions for Coverage - Subpart C Patient Care / Patient Plan of Care 494.90(a)(6)

Psychosocial statu

The interdisciplinary team must provide the necessary monitoring and social work interventions. These include courseling services and referrals for other social services, to assist the patient in actieving and sustaining an appropriate psychosocial status as measured by a standardized mental and physical assessment tool chosen by the social worker, at regular intervals, or more frequently on an as-needed basis.

Supplementary Information - Section II / Summary of the Proposed Provisions and Response to Comments on the February 4, 2005 Proposed Rule

CMS Response:

In response to the large number of comments, and in light of current academic research supporting social service interventions to improve patient care, we are adding a social services component, called "psychosocial status" to the plan of care requirements at 494.90(a)(6). We are requiring that a standardized tool, chosen by the social worker, be used to monitor patient status, and that counseling be provided and referrals be made as appropriate.

The standardized tool should be a professionally accepted, valid, reliable tool, such as the SF-36, and should relate to the patient's functional health and well-being. The tool must be used as a monitoring aid that assists in determining the patient's psychosocial status. The SF-36 model uses metrics that measure physical health as related to functional level and presence of pain, and mental health as related to social functioning, emotional and mental health. Reliability and validity studies have been performed for this instrument. More information about SF-36 may be found in numerious articles or on the web at yews 4-36 optoback §F36 string. The SF-12 survey form was derived from the SF-36 form and scales the 36 question survey down to a 1-page, 2-minute version. However, we are not specifying which tool must be used in order to allow flexibility and to limit the amount of burden. The choice of which standardized tool to use is best left to the facility social worker.

Phase III ESRD Clinical Performance Measures in effect April 1, 2008

Assessment of Health-related Quality of Life (Physical & Mental Functioning) – Facility Level: Percentage of diapsis patients who receive a quality of life assessment using the KDQOL-36 (36 question survey that assesses patients' functioning and well-being) at least once per year.

You can read about CPMs and download the latest table of them from: http://www.cms.hhs.gov/CPMProject/.

Quality of Life Assessment Tools Version 5-2-2008

1

www.kidney.org/professionals/cnsw/pdf/QOL_AssessmentTools.pdf





CNSW Care Planning Resource Toolkit

- 40-page document
- Citation of § 494.90 Condition: Plan of Care (CfC)
- Assessment to Plan of Care
- Social work Focused Criteria Care Plan Examples
- NKF/CNSW Outcomes Training Program Interventions
 - Phase 1 Interventions & Case Example using the CNSW Example Patient Assessment for care planning
 - Phase 2 Interventions & Case Example using the KDQOL for care planning
 - Phase 3 Interventions & Case Example using the KDQOL for care planning at the end of life

www.kidney.org/professionals/cnsw/pdf/CNSWCarePlanningResourceToolkit.pdf





CNSW Listserv & Archive

- Subscribe at <u>www.kidney.org/PROFESSIONALS/cnsw/listserv.cfm</u>
- Archive at http://listserv.kidney.org/scripts/wa.exe?A0=cnsw
- Log In (requires subscriber email address & password)
- Search by key word, author, date range (international sequence year/mo/day)

Item #	Date	Time	Lines	Subject	
023258	2008-11-22	18:23	223	Re: Question KDQOL	
023224	2008-11-20	16:33	426	Re: NASW Consultation & KDQOL 36 etc	
023226	2008-11-20	14:49	532	Re: NASW Consultation & KDQOL 36 etc	
023223	2008-11-20	14:28	383	Re: NASW Consultation & KDQOL 36 etc	
023216	2008-11-20	14:06	450	Re: NASW Consultation & KDQOL 36 etc	
023215	2008-11-20	13:34	376	Re: NASW Consultation & KDQOL 36 etc	
023040	2008-11-11	23:44	550	Re: KDQOL	
022977	2008-11-07	23:39	57	Re: KDQOL-36 Results	
022976	2008-11-07	23:34	751	Re: KDQOL-36 Interpretation	
022975	2008-11-07	20:37	317	Re: KDQOL36 & NASW Code of Ethics & Informed Consent	
022970	2008-11-07	14:46	630	Re: KDQOL36 & NASW Code of Ethics & Informed Consent	
022968	2008-11-07	14:34	648	Re: KDQOL-36 Interpretation	
022971	2008-11-07	13:47	493	Re: KDQOL-36 Interpretation	
022965	2008-11-07	13:09	863	Re: KDQOL36 & NASW Code of Ethics & Informed Consent	
022961	2008-11-07	11:08	26	KDQOL-36 Results	
022956	2008-11-07	10:25	176	Re: KDQOL-36 Interpretation	
022962	2008-11-07	10:03	591	Re: KDQOL-36 Interpretation	
022963	2008-11-07	10:00	556	Re: KDQOL36 & NASW Code of Ethics & Informed Consent	
022954	2008-11-07	09:31	543	Re: KDQOL36 & NASW Code of Ethics & Informed Consent	
022960	2008-11-07	09:02	558	Re: KDQOL36 & NASW Code of Ethics & Informed Consent	
022955	2008-11-07	08:48	193	Re: KDQOL-36 Interpretation	





Convert Longer KDQOL™ Translations to KDQOL-36

Comparison KDQOL-SF 1.3 and KDQOL-36

•	Ch	ine	se
	\mathbf{O}		

- Czech
- Danish
- Dutch
- English
- French
- German
- Greek
- Hebrew

KDQOL-SF 1.3	KDQOL-36		
1	1		
3 b	2		
3 d	3		
4 b	4		
4 c	5		
5 b	6		
5 c	7		
8	8		
9 d	9		
9 e	10		
9 f	11		
10	12		
12 a	13		
12 b	14		
12 c	15		
12 d	16		
14 a	17		
14 b	18		
14 c	19		
14 d	20		
14 e	21		
14 f	22		
14 g	23		
14 h	24		
14 i	25		
14 j	26		
14 k	27		
14	28 a (HD only)		
14 m	28 b (PD only)		
15 a	29		
15 b	30		
15 c	31		
15 d	32		
15 e	33		
15 f	34		
15 g	35		
15 h	36		

- Hungarian
- Italian
- Malay
- Polish
- Portuguese
- Russian
- Spanish
- Swedish
- Turkish

http://gim.med.ucla.edu/kdqol (register for downloads)





Other CNSW Resources

- CNSW Standards of Practice www.kidney.org/professionals/CNSW/form_standards.cfm
- CNSW's CQI manual www.kidney.org/professionals/CNSW/form_cqi.cfm
- CNSW's Outcomes Training Program (interventions) www.kidney.org/professionals/cnsw/otp.cfm
- NKF's KDOQI CKD Guideline 12 (functioning & well-being) www.kidney.org/professionals/Kdoqi/guidelines_ckd/p6_comp_g 12.htm
- Journal of Nephrology Social Workers (for current & archived issues, members)
 www.kidney.org/professionals/CNSW/JNSWonline/index.cfm
- Wellness Programming article (Nephrology News & Issues) www.kidney.org/about/central/pdf/wellnessProgramming.pdf





PedsQL: One Measure of HRQOL in Pediatric Patients

- Developed, copyrighted by James W. Varni
- Assesses HRQOL in children
- An ESRD version is available
- Examination copy available for 7 days

- Survey is for patients or parent (proxy)
- Target ages
 - Toddler (2-4)
 - Young child (5-7)
 - Child (8-12)
 - Adolescent (13-18)
- For license to use, contact@mapi-trust.org

www.pedsql.org







Introducing the Survey Process to the Interdisciplinary Team

Stephanie Johnstone, LCSW

FMCNA Regional Lead Social Worker San Diego



Engaging the Physician, RNs RD, and Technicians

- Provide data re: relationship of scores to survival, hospitalization, other outcomes (Lowrie, Mapes)
- Describe its value as the "third leg" of a stool re: assessment (lab values, patient appearance, selfreported symptoms of living with ESRD
- Have these team members take the survey substituting "patient" for a role applicable to their life (nurse, mother, etc.)





Engaging the Physician, RNs RD, and Technicians (cont.)

- Review the scores of one of your clinic's patients and that patient's experience of the survey with your team
- Ask the medical director to recommend that all patients participate and to write a letter to rounding physicians and patients





Engaging the Patient

- Describe the survey as "MD recommended" to help the team manage their health
- Use a simple one-page handout with bullets on its value:
 - A screener of many areas that affect their health and wellness that the team might otherwise miss
 - A survey that helps the team understand what is important to the patient so they can help him/her maintain quality of life





Engaging the Patient (cont.)

Teach against common distortions and anxieties

- No right or wrong answers—all we learn is valuable
- The SW is available to do the survey with you
- You know better than anyone how to answer

Encourage honest responses

– Finding areas where you struggle with your health can help us keep you well!





Rehearsing Your Approach to the Patient

"The medical team here uses the Kidney Disease Quality of Life survey to help us assess your overall health and well-being. We ask a series of questions at least once a year, more often if needed, to understand how things are going from your perspective. We then give you a summary of the scores and we all, including your doctor, work together to improve them. The survey takes about 15 minutes, is this a good time?

As you answer the questions, remember there are no good or bad answers-so be as honest as possible. It will help us to identify any area where you might be struggling with kidney disease so we can help improve things for you."





Framing the KDQOL-36 (From the CNSW Listserv)

"The governing body that licenses and evaluates dialysis clinics has changed the rules for the betterment of patient care. I am very excited about the changes and look forward to working with you under these new rules. We are going to be taking a more complete look at patients from a holistic point of view. Each of the staff who work with you will be concerned with your mind, body, and spirit. We want you to have the very best quality of life possible. I will be talking to you about some issues or concerns you may have and asking you a lot more questions. Anything you don't want to answer is fine. Shall we begin?"

-Mary Calzada, MSW, LCSW, posted 11/25/08





Using the Scores in Rehabilitation Planning

- Review scores with patients soon after survey is completed
- Focus on areas where things are going well
- Focus on areas where scores could improve
- Ask the patient to choose an area of most concern from below average score areas





Use a Solution-Oriented Approach to Intervening in That Area

- "What would you like to see different in this area a few months from now?"
- "How would your day-to-day life be different if this were better? What would you be doing?"
- "What steps are needed to get you to where you want to go?"
- "How might we partner together to reach your goal?"
- "Might we use your family/friends to support our plan?"





"I Want to Stop Missing Treatments. I Want a Transplant"

- Mr. Smith 62-year old diabetic male on dialysis two years
- Missed 4-5 treatments/month
- Felt disempowered and that all pleasure was removed from his life
- Wanted to live





Mr. Smith's Personal Steps to Success

- 1. Recognize "why" I miss treatments
- 2. Make a personal commitment to not miss any treatment for 30 days, see what happens
- Sign up for Transplant 101 class to see if it can help manage some of my fears of transplant
- 4. Talk to my doctor and other patients about life with a transplant





45 Days Later...

- Had made an appointment for "Transplant 101"
- Had missed NO treatments for 30 days
- Had significantly improved Quality of Life Scores on the re-measurement
- "The process allowed me time to reflect, understand, and gain hope. The partnership with my social worker was key—her encouragement motivated me to take steps forward toward better managing my health."

Mr. Smith





Conclusion

HRQOL is:

- Patient-perceived physical & mental function
- A way to assess chronic disease goals
- A predictor of hospitalization and death in dialysis patients
- Easy to measure using the KDQOL-36, a valid and reliable survey
- Actionable in the dialysis setting





CNSW National Membership -How to Best Stay Informed About the New Conditions

Ask your employer to fund part or all of your membership fee!

How do you join?

Go to www.kidney.org

or

Call (800) 622-9010

http://www.kidney.org/professionals/pdf/cnswform.pdf





Questions?

For more information, see KDQOL Questions and Answers

www.kidney.org/professionals/cnsw/pdf/KDQOL_QandA-Webinar11-18-08.pdf



