

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

Question	Response
Survey Ethics	
Should a patient be asked to sign a consent form if the KDQOL-36 is being used for patient care, not research?	Whatever consent process is used locally for collecting data for patient care should be used to collect KDQOL-36 data.
Key representatives from LDOs are on this call. You did not address informed consent as required for ethical practice. Why was this not addressed?	NASW's ethics consultant advised including a statement about patients being surveyed from time to time in the standard consent that dialysis facilities have patients sign. Patients have the right to refuse to complete this survey, just like they have the right to refuse any treatment
I have heard that facility consent forms do not cover this tool. Is there a consent form for this tool due to its evaluation and research aspect?	Although the KDQOL was initially used for research, this survey is being used in dialysis today as part of clinical care. Since CMS requires facilities to administer a patient satisfaction survey and staff may want to administer other surveys to save time and effort, a statement could be added to general consent forms that patients sign on admission.
Does a release of information form need to be signed by patient before administering the KDQOL?	You don't have to complete a release of information form unless you are sharing the data outside your facility. If you're referring to a consent form, refer to previous responses.
If the patient completes the entire KDQOL-SF 1.3 survey, is there an ethical obligation to score and help the patient understand his/her scores on the entire survey?	In a research study this would not be recommended. For clinical uses, it may or may not be appropriate.
Is it acceptable to use two different tools depending on the patient's language? Given the wealth of data supporting measuring HRQOL, it seems morally (and perhaps ethically) questionable to not offer a HRQOL survey to all patients based on lack of translation (particularly if there is one available).	There are multiple translations of the longer KDQOL-SF 1.3. The exclusion criteria were established to limit undue burden on facilities. However, it would be optimal to obtain a translation of the KDQOL-36 survey. If there is a translation of the KDQOL-SF 1.3, then a KDQOL-36 can be created from it by deleting questions not on the KDQOL-36.
Survey Development	
Is KDQOL 36 the same thing as KDQOL-SF?	The KDQOL-SF is a much longer survey. The KDQOL-36 includes a subset of questions from the KDQOL-SF. The most predictive items from the longer survey were kept in this shorter survey.
I have heard that the KDQOL was developed as a research tool and was not meant to be used to assess individual patients. The PCS and MCS scores that the KDQOL yields can only be used to assess populations, not individuals. Would you comment on this please?	You may be thinking about the SF-8 from QualityMetric which is a survey intended to only be used with very large populations. The KDQOL-36 includes the longer SF-12. The survey developers have said that this survey can be used to monitor changes in individuals.

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Survey Design	
In a Dutch study the discrepancy between <i>perceived</i> social support and the <i>actual</i> support received was a significant predictor of mortality (Boeschoten et al) Is this addressed in the questions?	There is a question on the KDQOL-36 that asks whether physical or emotional problems interfered with social activities and a question that asks how much of a burden the patient feels his/her kidney disease is on the family. The longer KDQOL-SF 1.3 produces a score for social support.
Has this quality of life measure been normed? This may have been stated, but I don't remember.	The KDQOL Working Group website at www.gim.med.ucla.edu/kdqol has a chart from the Dialysis Outcomes and Practice Patterns Study that has the means and standard deviations for patients based on age and gender. You need to register (free) to get an ID and password to be able to access the "Downloads" page where you can find this chart.
Is there a cost for the tool or for the results?	There is no cost for the KDQOL from the KDQOL Working Group website or for the report from the Life Options KDQOL-36 Online at www.lifeoptions.org/kdqol/ .
Survey Standardization	
Would the validity of the tool be compromised if patients only completed the KDQOL-36 items on a longer survey?	The responses should be minimally affected by whether the items are administered as part of the 36 item survey (KDQOL-36) or the longer KDQOL-SF 1.3.
If a contractor advises combining the SF-36 with the 24 kidney questions from the KDQOL-36, would this survey no longer be considered "standardized?" Would this survey meet requirements in the interpretive guidance?	We can't answer for CMS but whether the SF-12 (as is the case in the KDQOL-36) or the SF-36 are asked first should not substantially impact on responses to the symptom/problem, effects of kidney disease and burden of kidney disease items.
Finding the KDQOL & Scoring Tools	
Can we get a hard copy of the test or is it only available online?	You can download a PDF of the KDQOL-36 from the KDQOL Working Group website "downloads" page at www.gim.med.ucla.edu/kdqol . You will need to register (free) to get an ID and password to access this page. You can save the PDF to your computer to print out whenever you need it. The Life Options KDQOL-36 Online at www.lifeoptions.org/kdqol/ is available to use to directly respond to questions or to score the surveys after patients have completed the hard copy.
Where is the scoring tool located?	You can find an Excel scoring template for the KDQOL-36 on the Downloads page after your register (free) on the KDQOL Working Group

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	website at www.gim.med.ucla.edu/kdqol or you can score the survey online on the KDQOL-36 Online at www.lifeoptions.org/kdqol/
Survey Administration	
When did this become mandatory?	The new clinical performance measures took effect April 1, 2008. One includes measurement of physical and mental functioning using the KDQOL-36. The new Conditions for Coverage require measurement of physical and mental functioning as part of the Condition for Patient plan of care. These took effect 10/14/08.
What date do the KDQOL guidelines go into effect now or when CROWNWeb is available?	The effective date for the new regulations is October 14, 2008 and the CMS clinical performance measure was endorsed April 1, 2008. CROWNWeb may not collect this data until 2010. However, social workers should be completing some surveys every month, starting with the most vulnerable patients, including those who are new but have been on dialysis 3 months and those that are unstable.
When and how often should the KDQOL-36 be administered	The KDQOL-36 should be administered at "baseline" 3 months after starting dialysis and periodically after that (annually or as needed). Examples of an "as needed basis" would include those patients whose HRQOL may have changed.
Are social workers supposed to be doing the KDQOL now or in the spring when Crown Web is up and running?	The interpretive guidance says you administer the survey now. The clinical performance measure that required facilities to use this survey took effect 4/1/08. Be aware of the patients that you can exclude and recognize that patients have the right to refuse.
How are you suggesting this survey be introduced?	See the documentation for professionals on the KDQOL-36 Online at www.lifeoptions.org/kdqol/ .
Should the KDQOL-36 be administered to HD and PD patients at home and in-center?	The KDQOL-36 should be administered to both home and in-center patients. It can be administered either at home or in-center. The advantage of administration at home is that responses are less likely to be influenced by socially desirable response pressures. The advantage of in-center administration is that participation rates are likely to be higher. Ideally, the same method of administration should be used whenever possible with the same patient over time because mode could systematically influence responses.
How should patients be instructed to answer questions on the survey when they seem confused	Whenever possible, KDQOL data should be collected by a trained surveyor to minimize bias. If it

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about how to answer?	is necessary to help a patient complete the KDQOL, you should: 1) Speak loudly and clearly and verify that the patient can hear you; 2) Do not interpret items. Ask the patient to respond to what he or she believes the survey asks; and 3) Repeat response options as often as needed, keeping any frustration out of your voice. See professional documentation at www.lifeoptions.org/kdqol/pdfs/kdqol36_pros.pdf
Patients often express frustration with trying to sort-out the effects of other illnesses they are experiencing from those that they experience due to dialysis, i.e. "If it was just dialysis I would have no issue with pain- it is the arthritis that troubles me".. How do I help them sort that out...or is it necessary to sort it out?	Encourage the patients to read the questions carefully. Those that specifically mention kidney disease should relate to how much kidney disease bothers patients. So far as symptoms, patients should report how much any symptom bothers them whether that symptom is related to kidney disease or another condition. Pain is a perfect example of a symptom that patients may not mention if it is not related to kidney disease. If the physician knows the patient is in pain, pain can be treated to improve sleep, mood, activities, and even coming to dialysis and staying for the full dialysis treatment.
Question #35 on the KDQOL-36 asks about the effects of kidney disease on a patient's sex life. If a patient has no sex life (no partner or member of religious order, etc.), how should this question be answered (low, middle response, left blank)?	The question asks how much kidney disease bothers you in your sex life (not at all, somewhat, moderately, very much, extremely). The patient should choose the answer that most closely matches sense of how their sex life is bothered by kidney disease. If someone is not sexually active because of their kidney disease they might interpret the disease as bothering them in this regard. If they are not sexually active but it is unrelated to kidney disease they might say they are "not at all" bothered. Someone may have lost interest in sex when they developed kidney disease and they should mark how much this loss of interest bothers him/her.
The majority of my patients are elderly (70's and 80's) with multiple health problems and frequent hospitalizations. The patients and treatment teams at my two clinics are well aware of the multiple health and related social problems and how patients' lives are affected. I am concerned about asking most of these patients to complete this survey when the responses are already known and well documented for most patients, and the KDQOL	A patient always has the right to refuse to complete the survey, but the clinical performance measure will collect data on patients who took the survey in the data year. You must offer the survey before you can ethically say the patient refused. The way the survey is presented can affect a patient's willingness to complete it. If it's presented as a way to help the team identify previously unidentified problems and target efforts more specifically, even

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will not impact patient care. I believe the possibility exists that asking my patients to complete these assessments may alienate them as they have been patients at the clinic for several years and may question staff about the competence of the team. One pt. told me that she did not like the questions on the survey. How can this issue be addressed?	elderly debilitated patients may consent. Patients who are debilitated may be in pain and might not think to report their pain to the nurses or doctor because it's not kidney pain. Using the KDQOL-36 to identify this pain could allow better pain management which may improve a patient's mental and physical health, sleep, and more. A debilitated patient may be fatigued because of anemia. Improving anemia management may help the patient be less debilitated and be more social. The only way to know for sure how a patient is feeling is to ask.
I would suggest having the MD hand out this survey at his rounds or outpatient clinic appointment. We would also address this in a peer group pre dialysis education session inviting people to fill them out when entering dialysis with examples like Stephanie told us about!	Having the doctor encourage patients to complete the survey could have a significant impact on patients' willingness to complete it. Although the ESRD regulations do not require completion of the survey until after dialysis is initiated, having baseline data could be helpful.
Which form do we use - UCLA or Life Options? What date/when should the KDQOL be initiated?	Both websites have the same survey. The survey should be administered any time after the 3 rd month of dialysis. Clinics should be administering surveys to their patients a few at a time. The effective date of the regulation requiring measurement was 10/14/08.
Does the KDQOL or PedsQL take the place of the initial psychosocial assessment? If not how does the QOL and psychosocial work together?	No. Because the KDQOL has 5 different scales, it should supplement what is learned by all team members during the interdisciplinary patient assessment and enhance others' assessment areas, not just the psychosocial assessment.
Any tips on how to start implementing KDQOL, i.e., new patients first or at annual assessment time?	New patients should have a KDQOL-36 during the 4 th month on dialysis and at least annually thereafter. Established patients (in caseload October 14, 2008) can be surveyed a few at a time over the next year, possibly on their anniversary date.
When CMS comes to facilities for survey is it allowed to wait for annual assessment and care plan to do KDQOL?	If a surveyor comes to your facility, he/she will expect your facility to have a plan for how to complete all patient assessments, plans of care, and KDQOL-36 surveyors on established patients (patients in your census prior to October 14, 2008) by October 14, 2009. Your facility would be expected to be working that plan.
When should KDQOL be first administered to new patients? The slide mentioned not using KDQOL with patients on dialysis <3 months. The initial Plan	The interpretive guidance takes into consideration that the survey developers recommended not to complete this survey during the first 3 months of

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of Care asks for KDQOL scores.	dialysis. In fact, it states that the survey should be completed in the 4 th month of dialysis.
Working at the facility with 150 patients, I see that it'll be difficult to administer and give adequate attention to all patients in the course of month. What do you think about administering KDQOL to different patients in different months (e.g., 15 patients each month)?	Start with the new patients who initiated dialysis on or after October 14, 2008 or unstable established patients. With new patients, you should have them take the KDQOL survey in the 4 th month after starting dialysis. Established unstable patients can take it any time.
I have a case load of 140 when full. With all of the demands, I have no idea how to complete all of the tasks.	Others have found it helpful to triage patients into those who are in their 4 th month of dialysis, those may have had a change that could affect their HRQOL, then those are scheduled for their annual assessment and plan of care, and then those who appear to be stable and who aren't scheduled for assessments or care plans right away. We would advise against doing all assessments or KDQOL-36 surveys the same month. On patients in your caseload prior to October 14, 2008, your team can do their assessments and plans of care, including the KDQOL-36 surveys around their anniversary month. All established patients should be in the system by October 14, 2009. Advocate with your management to allow someone else to do those tasks that do not require a social worker's education and skills to do other tasks. Use the rationale that tasks that must be done by a social worker should be done first to comply with federal regulations.
Everything discussed is my heart and passion and a dream to engage patients in such meaningful conversations to improve QOL. As a social worker new to dialysis, I'm wondering how other social workers have managed all the demands of the job in order to make this a priority.	Advocate with the facility manager or administrator for time to administer the survey and explain results of surveys to patients and staff. Otherwise, there is a risk that the ESRD surveyor could cite the interdisciplinary team for not complying with the plan of care requirements in the CfC and the governing body for not having enough staff to meet the patients' clinical needs.
Per CfC is the KDQOL supposed to be given on the patient's personal annual anniversary date or can a facility do the whole clinic the same time each year?	The interpretive guidance does not state when the survey should be done other than annually. Others have reported that it's easier to do a few surveys a month rather than doing all clinic patients at one time, but this is left up to facility policies.
Can we do the KDQOL more than 15 days prior to a care conference?	Yes. You can administer the KDQOL-36 any time after the patient has been on dialysis 3 months. The new CMS clinical performance measure requires annual (or as needed) administration of this survey for all patients who do not meet the exclusion

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	criteria. The survey can be administered as needed to measure changes related to health changes and/or interventions.
Who is responsible in entering the data?	The CfC does not specify who is to enter the data. Data entry should be done by an accurate typist who understands privacy and confidentiality.
In Canada we follow our patients as Pre-Renal Insufficient until they are on dialysis and then from there on. When we do our initial psychosocial assessment patients are not on dialysis and may not be for months. Can we use this tool for PRI patients who are not yet on dialysis to assess risk and QOL?	The KDQOL-36 and the longer KDQOL surveys have been used with patients who are not yet on dialysis. The Conditions for Coverage apply only to dialysis facilities and dialysis patients. However, KDOQI Guideline #12 recommends administering a survey of physical and mental functioning prior to dialysis initiation and as needed as the patient's health changes and interventions are tested.
Can the survey be given to the patient to take home and bring back completed? What if the patient fails to bring back the completed survey?	Patients can take the survey home. However, when they do, there is a risk that someone else will complete it for them and invalidate the answers.
Who and how is the survey to be administered? Are these to be administered by the social worker only?	The Conditions for Coverage and CMS clinical performance measures do not address who should administer the survey. The survey can be administered by anyone, including self-administration. The survey developers suggest that a third party vendor administer the survey by mail or phone or a combination of the two. However, in most dialysis clinics the patient can self-administer or a trained staff member can assist the patient who cannot self-administer to assure fast response. The social worker can use the time it takes for this survey as a patient contact and may obtain unique information from the survey that will help him/her provide more targeted interventions. Review the documentation for professionals on the KDQOL-36 Online at www.lifeoptions.org/kdqol/ .
If there is a BSW in the unit, would that be a good use of their education and talents?	There is no requirement for who can/should administer the survey or enter the data. This would depend on facility policy.
Can social work techs administer the survey or only social workers?	The CfC requires the social worker to choose the survey but is silent on who should administer it. Administering and discussing the scores with patients could be counted as a social worker-to-patient contact and may yield information that a social worker needs to know.
If the patient refuses once, should he/she be invited to complete it at a later time?	If the patient refuses to complete the survey, ask why. It may be that he/she can't see well enough to complete it (or can't read and is embarrassed), can't

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	think clearly enough on dialysis, or doesn't want to complete it in the treatment area. Once barriers are overcome, the patient may be willing to complete the survey. If not, tell the patient this survey is part of dialysis care and you'll be asking again next year.
When you talk about doing the survey with patients, are you meaning actually asking them the questions? Shouldn't we avoid potential bias? Do you mean reviewing the survey after they have completed it?	Read the suggestions for administering the survey at www.lifeoptions.org/kdqol/ under documentation for professionals. Review the survey results with patients as soon as possible afterwards and seek goals and start interventions. Timely follow-up should increase patient willingness to retake the survey later.
It sounds like Stephanie was talking about sitting down and administering the survey with pts. The information I read encouraged not to do that unless absolutely necessary so we are not skewing patients' answers or patients' answering how they think we want them to answer. So is it better to administer it with patients?	Self-administration is the ideal. However, if an interview is necessary because patients are unable to complete the survey independently, there are guidelines about conducting interviews to minimize any potential bias in documentation for professionals at www.lifeoptions.org/kdqol/ .
Is there a benefit in taking the KDQOL when quarterly lab work is done to see how the KDQOL correlates with physical signs?	Some symptoms and scale scores could change as lab values change.
Exclusions from the KDQOL-36	
Didn't it say on one of the first slides that this survey can't be done on patients that are under 18, have cognitive problems or dementia, don't speak English, have been on dialysis for less than 3 months, or if they refuse?	Those are the exclusion criteria for the KDQOL-36. There are other HRQOL surveys for pediatric patients and there are multiple translations of the KDQOL on the KDQOL Working Group website at www.gim.med.ucla.edu/kdqol/ . If a longer translation is available, you note which questions the patient should not to answer—ones not on the KDQOL-36.
Pediatric centers seem to disagree about whether we are exempt from using a QOL tool because our patients are under age for the KDQOL - or whether we simply need to find an alternate tool that is validated for our patient population. Any advice?	Pediatric facilities do not have to administer the KDQOL-36 with patients <18. However, the CfC interpretive guidance states that they should administer another standardized physical and mental functioning survey validated for the pediatric population.
What other QOL assessments are available for patients under age 18, other than the PedsQOL? Where do we get these assessments?	You can find a database of HRQOL surveys at www.golid.org/ that you can search by population or disease.
I have a mentally retarded pediatric patient. Do I need to survey her, her parent, or skip it?	This patient would meet the criteria for exclusion from the requirement to complete the KDQOL-36 based on her age and cognitive impairment
Most of my nursing home patients will be unable to complete this survey due to cognitive issues.	Patients who have cognitive impairments are excluded from completing the KDQOL-36 according

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	to the CMS clinical performance measure.
Is it okay to have a patient's family member complete the survey if the patient has dementia? Or do we just exclude them from the survey?	Patients with dementia are excluded from completing the KDQOL-36.
Surveying Special Populations	
How should we administer the KDQOL to people who are visually impaired? If we want our patients to complete the surveys independent of us so we do not influence their responses, should we send it home with a family member to help them?	A family member may complete the survey for the patient or the patient may respond differently with a family member from how he/she would respond if a staff member helps. Another option is to have an independent survey vendor conduct a telephone interview.
How is this tool helpful when many patients are in nursing homes, and mostly bed bound for the rest of their lives?	If patients are cognitively impaired or psychotic they do not need to complete the KDQOL-36 (excluded). However, the US Renal Data System 2008 Annual Data Report, only 6% of patients are in nursing homes at treatment initiation. Some bedbound patients in nursing homes are bedbound because of treatable medical conditions or physical debilitation that could be improved. The KDQOL-36 may identify a previously unidentified problem that could be treated.
Survey Translations	
Do we need to complete the KDQOL for Spanish speaking only patients at this time? If so, how do we process the results and summary of care? We can provide them with the results but they will not be able to read the English results.	There are several Spanish dialect surveys on the KDQOL Working Group website so these patients would not be excluded from completing the KDQOL-36. Currently there is not a report for the scores in Spanish. However, you could translate the Life Options report for patients until the report is available in KDQOL-Complete in Spanish in 2009.
When did you say the Spanish translation will be available?	There is a U.S. Spanish translation of the KDQOL-36 survey posted on the KDQOL Working Group website at www.gim.med.ucla.edu/kdqol . The 4-page results from Life Options will be available in early 2009.
Which Spanish version is recommended?	It depends on which type of Spanish your patient speaks. A new U.S. Spanish translation of the KDQOL-36 was recently posted on the KDQOL Working Group website at www.gim.med.ucla.edu/kdqol .
Are the results for the survey now available in Spanish?	The results will be available in Spanish in 2009.
How will we be notified that the Spanish survey results are ready in 2009?	This will be posted on the CNSW listserv website.
Is there a translation of the KDQOL in	These translations are not yet available. However, a

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Laotian/Hmong? Any possibility of a Creole Haitian translation of the KDQOL-36 becoming available? I noticed that Tagalog is not posted as one of the language translations available. Will Tagalog be added and available at some point?	provider could review what patients its facilities treat and follow the protocol on the KDQOL Working Group website at www.gim.med.ucla.edu/kdqol to obtain a translation.
Google translate does a decent job of translating documents and there is a large range of languages.	Internet translation tools are intended to be used to translate a word or brief phrase. There is an established process for translating a survey like this one that includes forward and backward translations and pilot testing with patients to assure that the translation is accurate. However, a provider can follow the protocol on the KDQOL Working Group website at www.gim.med.ucla.edu/kdqol to obtain a valid translation.
I am wondering how the Dutch version (of the KDQOL) is related to the American one. It would be very interesting to see whether the results in my patients would be very different? Alas DOPPS didn't have a Dutch league but maybe other countries involved are interested? It would be so nice to relate the international perspective at some given point in time!	You might want to visit the DOPPS website at www.dopps.org to contact others to compare the results to those in the Netherlands.
Survey Scoring & Interpretation	
Are specific problems assessed by the instrument, or are these general areas and specifics must be gleaned?	There are 5 problem areas that the survey addresses: Physical Health, Mental Health, Effects of Kidney Disease, Symptoms/Problems, and Burdens Of Kidney Disease. Scores are reported as numbers. The higher the number, the better the score. The Life Options KDQOL-36 Online at www.lifeoptions.org/kdqol/ currently provides a report with the patient's scores, the mean for that scale, and the risk level based on the patient's age, gender, and diabetes status. Specific questions (especially symptoms/problems) should be shared with other team members.
Is there a manual that shows what questions are used for which different scales?	These are the items and scales they relate to: <ul style="list-style-type: none"> • Items 1-12: SF-12 (PCS & MCS) • Items 13-16: Burden of kidney disease (k=4) • Items 17-28: Symptoms/problems (k=12) • Items 29-36: Effects of kidney disease (k=8)
Can we discuss scoring the KDQOL?	There is an Excel scoring template that you can download from the KDQOL Working Group website (www.gim.med.ucla.edu/kdqol) after you register (free) and use the ID and password to get

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	to the Downloads page. Be sure to choose the KDQOL-36 template. The KDQOL-36 Online at www.lifeoptions.org/kdqol/ currently scores the survey when a patient answers all questions and provides a written report with the patient's score, the mean score, and the patient's risk for hospitalization and death in one of 3 tiers.
Where do we get the software to download the results of the questionnaire?	The KDQOL-36 Online at www.lifeoptions.org/kdqol/ currently scores the survey for you when you enter the patient's responses to all the questions. See the previous question above about where to download the Excel template.
I do not know how to use the score. Isn't there a simple key?	You may want to review the documentation for professionals on the KDQOL-36 Online at www.lifeoptions.org/kdqol/ . It contains information about the survey and suggestions for how to administer it and use the scores for targeting interventions to improve care and HRQOL. The KDQOL-36 Online generates a report that gives suggestions for how to improve the scores.
What guidelines do we use for scoring? How do we know if a score is too low/average, etc.?	A chart that shows DOPPS means and standard deviations by age and gender is posted on the "downloads" page of the KDQOL Working Group website at www.gim.med.ucla.edu/kdqol/ . You need to register (free) to get an ID and password to access this page. One standard deviation either side of the mean is considered average. The KDQOL-36 Online at www.lifeoptions.org/kdqol/ scores the survey for you and gives you a report that analyzes the data and provides tips for improving scores. It does not save patient data.
How do we get the database for the national averages?	Go to www.gim.med.ucla.edu/kdqol/ , register for an ID and password (free), and click on the Downloads page. There is a chart from the Dialysis Outcomes and Practice Patterns Study with means and standard deviations for male and female patients of different ages. The KDQOL-36 Online at www.lifeoptions.org/kdqol/ scores it for you.
Should we be focusing on comparing the PCS and MCS to the scores of the same sex/diabetic or not/age group average scores OR wanting above the PCS value of 43 and MCS value of 51? What should be documented in the CMPA assessment?	Compare all the patient's scale scores with the average (mean) score for someone like him/her (age, gender, diabetes status). The PCS and MCS scores reported in the research were not adjusted for age, gender, or diabetes status.
Does a score greater than 75 mean we should not	You should compare patients to others like them.

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be concerned; whereas a score less than 50 means we should be concerned?	What would be a low score for someone who is 25 would be an average score for someone who is 75. If you use the KDQOL-36 Online at www.lifeoptions.org/kdqol/ , you will currently get a printed report that explains the scores.
The POC asks for the pt scores to be entered and for target scores. Where do we get the target scores?	There are no static target scores for HRQOL as there are for lab tests, blood pressure, etc. The KDQOL-36 Online at www.lifeoptions.org/kdqol/ provides the mean scores for someone his/her age, gender, and diabetes status along with the patient's score and whether his/her risk is average or better or worse than average.
Do we get a print out for each patient?	You do if you're using the KDQOL-36 Online at www.lifeoptions.org/kdqol/ .
I love the "These things may help" section on the KDQOL-36 Online. At the beginning of the PCS and MCS score, the indication about the risk of hospitalization and life expectancy is too direct. Shouldn't these risks be left to the interdisciplinary team to discuss? Why not just include "What is a PCS/MCS Score" in the report without being so direct?	<p>The scores on the KDQOL-36 Online at www.lifeoptions.org/kdqol/ are adjusted by age, race, and diabetes status for each individual. Without knowing the norms for a patient of that age, gender, and diabetes status, the IDT may not be able to determine whether a patient's risk is low, average, or high. The range of average scores on the KDQOL-36 is very broad, so someone who falls below those scores is at significantly higher risk of hospitalization and/or death.</p> <p>The predictive value of these scale scores has been proven multiple studies on tens of thousands of dialysis patients. Patients who respond to questions on the KDQOL-36 with the low options know they don't feel good so we're not telling them anything new. However, we can give them hope. There are interventions that have been shown through research to be effective in improving scores.</p> <p>No one wants to be the one to share "bad news." A doctor may not want to tell a patient he/she has kidney failure (or cancer) or some other scary illness, but when there is treatment available, if we have a positive attitude, and if knowing the risk might motivate a patient to change a risky behavior, we have to decide whether our reluctance to share these facts with patients is to protect them—or us.</p>
I notice with patients so far is that some when you ask them how their health is and you know they are very sick and they say their health is "good." How is	The patient's perception is the key. Staff perception of a patient's physical and mental functioning is often quite different from a patient's self-report. The

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that going to skew the results? They are not good, but they think they are. How they perceive it...is that the key? Is it good news that they see it good even if it is not?	patient's perception is what has been found to predict hospitalizations and death.
I recently had a patient complete the SF 36 at the beginning of one month, scoring 21 in PCS and 61 in MCS. One month later the KDQOL was completed by same patient and yielded PCS of 35 and MCS of 53, Symptoms 79, Effects 84 and Burden 93. This patient has described for years that her other health issues bother her, not her dialysis regimen. Do you think that the difference in these scores over a 26 day period reflects the specificity of the KDQOL questions, versus the generality of the SF 36 questions?	The SF-36 is a survey that asks generic questions. The KDQOL-36 is a kidney-specific survey that contains 12 of the SF-36 questions plus 24 kidney-specific questions. HRQOL surveys provide unique data on patients that isn't collected any other way. The KDQOL scoring is based on 100 points per question. The number of points assigned depends on the number of possible answers in that question. The highest number of points is always awarded to the most positive choice so higher scores are always better.
Isn't there a way to put the KDQOL-36 on a computer program that will allow data entry at chairside and that will score the survey?	See vendors such as assistTek at www.assistek.com/ . In the spring 2009, Life Options will offer the KDQOL-Complete , which will allow a clinic to score <i>all</i> patients, save the scores, and it will generate reports for individual patients or for the entire clinic census. The scoring report will also be offered in Spanish and possibly other languages. If you have a tablet or laptop PC patients could take the survey independently online. NOTE: You would need to follow infection control procedures when passing the computer from patient to patient.
Is it possible to order the scale columns on the scoring template to correspond with the score sheet handout?	This suggestion has been forwarded to the KDQOL Working Group .
As we use the KDQOL over time to assess for improvement in scores, what is considered significant? A 1 point increase, 5 point increase?	Each 1 point improvement in the physical component summary score reduces both the relative risk of death and hospitalization 2%. A 1 point improvement in mental component summary score reduces the relative risk of death 2% and the relative risk of hospitalization 1%. If the death risk now is 20%, improving the patient's PCS or MCS score could drop the patient's death risk for the patient would drop from 20% to 19.6% (20% x 2%).
Is a clinically significant change a standard deviation of 10 points?	An improvement of even 1 point on PCS or MCS scores can reduce the patient's relative risk of hospitalization and death.
Will the Life Options site allow users to "skip" a question in the future and still obtain a score?	The Life Options KDQOL-36 Online at www.lifeoptions.org/kdqol/ does not currently allow users to skip a question and obtain the score and the report. In the future, the KDQOL-Complete will

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	score the survey even if a patient skips a question. In the meantime, you can use the Excel template on the “downloads” page of the KDQOL Working Group website at www.gim.med.ucla.edu/kdqol to enter the data and score the survey. You will need to register (free) and use the ID and password to access the “downloads” page.
How do you score missing data?	Scale scores can be computed if at least one item in the scale is answered. The scores are computed as the average of the answered items. For example, if there are 5 questions in a scale and 4 are answered, the maximum total points to use in the denominator is 400 instead of 500.
It would be helpful to include descriptive statistics by gender, diabetes and age on the status sheet. Can this be done?	<p>If you're referring to having the patient's gender, diabetes status, and age print on the Life Options report as entered, this has been added. There is a space to write the patient's name on the report. KDQOL-Complete will save the data on a secure website so scores can be tracked and trended and used for individual care planning as well as for quality assessment and performance improvement (QAPI) activities.</p> <p>Life Options cannot give you the means and standard deviations for all the scales by age, gender, and diabetes status. This data belongs to Arbor Research. Medical Education Institute was not given permission to share it.</p>
Are there tables to show what is normal, above normal, below normal, etc?	See the DOPPS data chart on the downloads page from www.gim.med.ucla.edu/kdqol/ or use the Life Options KDQOL-36 Online at www.lifeoptions.org/kdqol/ to obtain scores adjusted by age, gender, and diabetes status reported in level of risk.
How do you use the KDQOL-36 template on the KDQOL website and what scores are worse than average?	<p>The UCLA website at www.gim.med.ucla.edu/kdqol/ has an Excel scoring spreadsheet with an example and instructions. There is also a SAS program on the site to score the KDQOL-36. There are 5 worksheets:</p> <ol style="list-style-type: none"> 1) Raw – data entry sheet 2) Convert – information only (calculates) 3) Score – provides points per question 4) Scale – provides 5 scale scores per patient 5) Stats – provides mean, median, standard deviation scores (facility aggregate) on all scales

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	See www.lifeoptions.org/kdqol/ for interpretation of the scores.
After you put the answers in the Excel spreadsheet & it does the computations how do you know what the scores actually <i>mean</i> ? I have the "Means & Standard Deviations for KDQOL Scales," but how does one know what the scores indicate in terms of how we interpret them with the patients?	See the Life Options website for interpretation of the scores at www.lifeoptions.org/kdqol/ .
Will the data be stored for one to access in the future?	The Excel template from the KDQOL Working Group website at www.gim.med.ucla.edu/kdqol/ stores the data. The Life Options KDQOL-36 Online at www.lifeoptions.org/kdqol/ does not. However, the KDQOL-Complete from Life Options in 2009 will store data. There is a sample patient tracking worksheet on KDQOL-36 Online . You can use this or create your own way to track data if you're not using the Excel template until the KDQOL-Complete is available in 2009.
On the web site I find Spanish versions but none state that they are a version of the KDQOL-36. Can we use the Life Options web site to enter the answers that were received in Spanish?	The KDQOL-36 items are a subset of the items in the KDQOL-SF 1.3. A Spanish language version of the KDQOL-36 is posted on the KDQOL website. You can enter the responses on the Spanish survey using the Life Options KDQOL-36 Online at www.lifeoptions.org/kdqol/ . This site does not have a Spanish version of the patient score report. A Spanish report will be available in KDQOL-Complete in the spring of 2009. You could use an interpreter or translator to share the scores and recommendations with the patient.
If you delete questions that are not on the KDQOL-36 from a translation of the longer KDQOL survey posted on the KDQOL, would that translated version of the KDQOL-36 survey be reliable and valid?	If the translation was done correctly, would be as reliable and valid as the English version.
Is any work being done to relate or compare the individual KDQOL results for patients on dialysis with patients who are candidates for renal transplantation or to follow up with patients post transplantation?	The KDQOL has been done comparing dialysis and transplant patients. You can find these on www.pubmed.gov using the search string "KDQOL dialysis transplant."
Survey Documentation/Privacy/Confidentiality	
What about confidentiality in the hemodialysis setting for both KDQOL and completion of the comprehensive assessment?	Patients should always be asked if they feel comfortable discussing a sensitive topic in the treatment area. Patients have the right to talk with staff in a private area and facilities must have space available for private conversations under the new Conditions for Coverage. All medical records

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	(including the KDQOL) should be maintained in a secure manner and only those staff members who have a need to know for continuity of care should have access to any medical records.
Should we store actual answers in the patients' charts?	Yes, include the scores in the patient's medical record along with the mean score for someone their age, gender, and diabetes status and their risk level. With education about what scores mean, the team should find ways to use their unique skills to improve patients' HRQOL and outcomes.
Where should completed surveys be filed?	They should be kept in the chart or in a locked storage area based on your facility's policy.
Where in the medical record should the scores be documented?	This would depend on facility policy related to documentation. However, since the Condition for Plan of care requires that physical and mental functioning be measured, it seems reasonable to document the 5 scale scores, the mean, and the patient's risk level.
Should we discard original surveys or keep it in the social worker's office?	Do not discard the surveys. The questions on them are a goldmine of information. Store them in the chart or in any secure location based on facility policy.
Should the survey be filed in medical records after the plan of care meeting is completed?	The survey should be used as part of the plan of care meeting. Where to file the survey would depend on facility policy.
Where do we put the completed KDQOL in the chart?	The scores and what they mean as well as IDT plans for improving them can be put in the chart where data on plan of care is charted.
What kind of documentation does CMS require around the use of the KDQOL? For example does it have to be in their chart or do we have to have something documented to check if they had taken the survey?	The requirement is under the Condition for Patient plan of care. You should report the scores, means, and risk level as part of POC along with mutually agreed goals and actions planned by the IDT.
If we can't place the completed KDQOL in the medical chart, where do we place it? The new Conditions of Coverage tell us not to keep separate files but to place all pt information in the medical chart.	The CfC requires that records be centralized and that members of the IDT need to have access to them. If the chart indicates where the survey is stored, that would meet these requirements.
If clinics are putting the KDQOL-36 results in the care plan, are target scores being listed (i.e., physical component and mental component)?	From the FAQ on www.gim.med.ucla.edu/kdqol/ "We believe that having the scores in the medical record is an exciting possibility for maximizing the usefulness of health-related quality of life data in clinical practice."
If surveys or scores are in the medical record, is it a	HIPAA does not prevent members of the healthcare

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breach of confidentiality to allow staff to read the patients' answers?	team who need information for continuity of care to see pertinent medical records.
The KDQOL does assess a patient's mental health. I am concerned that I am required to enter all results on every patient including the patient's name. Shouldn't this information (mental health) be protected under HIPAA? I feel we should code the patient's identity so that it is protected.	HIPAA protects all patient medical records, including the KDQOL. Therefore only those staff members with a need to know for continuity of care should have access to the scores. Since the scores are used for plan of care, it is important that other members of the IDT have access to them, know what they mean, and set goals and interventions for possible ways to improve low scores.
Yes, the medical chart is safe for HIPAA, but my company has directed that the scoring be done on spreadsheet on computer. Our computers are not protected as they are shared and passwords must be kept public. Any suggestions for getting through to corporate on handling this.	The CfC interpretive guidance states when there are electronic medical records, there should be passwords and security that limit access to those that need to know. Every dialysis clinic should have a HIPAA privacy officer who should be able to recommend how to protect privacy of this as well as other clinical data.
For those patients that are excluded or have refused to complete the survey, do we document such?	Document that the patient refused to complete the survey or which exclusion criteria was applied.
Are we required to (should we) track their scores over time on a separate spreadsheet?	This is not a Federal requirement under the Conditions for Coverage. However, developing a way to track individual scores over time would help the interdisciplinary team evaluate the success of interventions. Tracking aggregates scores could help the QAPI committee review and address scores that are not improving.
What information from the KDQOL-36 will be reported on CROWNWeb when that process starts? Will it be facility-level data or individual-level data?	Initially the clinical performance measure requires collection of facility-level data on how many patients took the survey in a year. It is anticipated that eventually patient-specific data will be collected.
How will CROWNWeb collect the information? Will we need to forward the information to CROWNWeb?	CROWNWeb will not be able to accept data right away for the KDQOL-36. Hopefully by the time it does accept data, a mechanism will be in place to allow batch data delivery.
Using the KDQOL-36 to Plan Care	
Is anyone addressing the KDQOL on the Care Plan or is it being used as a separate tool?	The Conditions for Coverage (ESRD regulation) published 4/15/08 requires this under Condition for Plan of care. The Interpretive Guidance states <i>"The social worker must have a system for routine use of the assessment survey, evaluation of the results, and incorporation of the survey results into the development and updating of the psychosocial portion of the plan of care."</i> Surveyors will expect the KDQOL-36 to be used in

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	<p>interdisciplinary team care planning. It is essential that all team members understand the scores and the risk levels to direct care they provide individually and jointly.</p> <p>The patient needs to be involved in care planning to assure that he/she agrees with the goals and is willing to take part in the interventions.</p>
Do we need to incorporate the KDQOL in our care plan for the patient or should we write a separate note about the results and interventions?	Since the CfC Condition for Patient plan of care requires use of a standardized survey of physical and mental functioning and since these surveys can be helpful to the IDT in planning care, it would seem appropriate to include the scores and risk level in the POC.
The POC asks for target KDQOL scores for the patient. Are these target scores the Life Options Average Scores?	The Condition for Patient plan of care expects targets on lab values and other clinical measures where targets are known. The KDQOL-36 scores should be adjusted at least by age and gender. The Life Options KDQOL-36 Online at www.lifeoptions.org/kdqol/ also adjusts the scores by diabetes status. You can report in your plan of care which of the three risk levels the scores reflect.
What happens when patients have lower scores? It is good for them to know that their scores are low?	If patients have low scores, they are at significantly higher risk of hospitalization and death. It would be irresponsible and possibly unethical to not tell the patient. Patients who fill out the survey in a way that yields low scores already know they don't feel good, but they may not know there's anything to help them feel better. The KDQOL-36 Online at www.lifeoptions.org/kdqol/ currently generates a report with tips for ways to improve scores.
Sorry the above question on Best Practice Guideline was mine and I wanted to ask if in due time we could link social work interventions with scores to see what works.... best	Some interventions that social workers do such as group counseling and adaptation training have already been shown to improve scores. As time goes by and more interventions are attempted, it will be important to track and trend effectiveness of those interventions.
I've had patients who have scored low on the KDQOL but have remained active and positive with their lives. Does this take into account that patients try to change despite answering questions resulting in low scores?{	The question might be whether patients are answering the survey more honestly than how they present themselves to clinic staff. Some patients "put on a happy face" (called "impression management") for clinic staff so staff believe they're doing better than they are. Patients perceptions reported on the survey have been linked with negative outcomes. If you discuss the report with

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	patients, the truth should come out.
Webinar and Resources	
Will a copy of the Power point slides be available after the webinar?	Yes. They will be posted on the CNSW website www.kidney.org/professionals/CNSW/conditions.cfm .
Other Issues	
What does DOPPS mean again?	This stands for the international Dialysis Outcomes and Practice Patterns Study. See www.dopps.org .
At our clinic we have a developed instrument and tool to measure KDQOL and have implemented it. Our question is this: Will we have to distribute your KDQOL-36 to our patients once it becomes available?	If your facility developed its own survey to measure HRQOL, to know it's measuring what you intended and that you'll get consistent results over time, you must have tested it for reliability and validity. The KDQOL-36 is a reliable and valid survey. It is already available in PDF to download from the KDQOL Working Group at www.gim.med.ucla.edu/kdqol/ or to complete online on the KDQOL-36 Online at www.lifeoptions.org/kdqol/ . The clinical performance measure requires annual or as needed measurement of physical and mental functioning using the KDQOL-36.
CAHPS is recommended from Network 11 as it addresses the CMS condition for change.	The CAHPS survey measures the patient's experience of care. It is a separate CPM requirement from the measurement of physical and mental functioning.
Is there a push toward ensuring that social workers are given ample opportunity to adequately address the new requirements that accompany this survey by reducing the clerical duties that often end up with the social worker?	The CfC requires that facilities provide enough staff to meet the clinical needs of patients and explicitly names social workers in this requirement. The preamble to the CfC encourages facilities to look at task assignment for social workers.
How is NKF approaching LDOs at Senior Leadership levels to reinforce social worker's role in dealing meeting the new CFCs?	CNSW has and will continue to lobby locally and nationally for the clinical role of nephrology social workers and to provide resources to help nephrology social workers limit their scope of practice to clinical social work.
Tell us more about social worker certification- I've not heard about this.	CNSW is working on a certification for experienced nephrology social workers. CNSW will share information when this is available.
How do you change set up for the CNSW listserv so that regular email is not being bombarded with emails?	There are two ways to handle this. <ul style="list-style-type: none"> • You can request the "digest" version following the instructions on each message. • You can set up a "rule" or "filter" to send emails into a folder you make on your email program. Look in <i>Help</i> for setting up a rule or filter.