

KDQOL Questions & Answers

Question	Answer
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.
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 for languages many patients speak. 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 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.
Survey Administration	
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 repeat use of the survey with the patient who has a significant life changing event (e.g., loss of spouse, loss of job, recent move to a nursing home) or a change in health status.
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 over time because mode could systematically influence responses.

KDQOL Questions & Answers

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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 (instead of with) 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 should patients be instructed to answer questions on the survey when they seem confused about how to answer?	Whenever possible, KDQOL data should be collected by a trained survey vendor to minimize bias. If it 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
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 person without a sex life determines whether kidney disease bothers them in their sex life or not whether they are sexually active or not. 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 active but it is unrelated to kidney disease they might say they are "not at all" bothered.
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?	The scores on the KDQOL-36 Online 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 <i>not</i> 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 <i>significantly higher risk of hospitalization and/or death</i> . 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.

KDQOL Questions & Answers

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	<p><i>We can give them hope</i> -- 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>
Survey Scoring	
Is there a manual that shows what questions are used for which different scales?	See www.gim.med.ucla.edu/kdqol . The FAQs on that site provide this information.
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 assisTek at www.assistek.com/ . In Spring of 2009, Life Options will offer the KDQOL-Complete , which will allow scoring of <i>all</i> patients in a clinic, and reports by patient or for the entire clinic census. The scoring report will also be offered in Spanish. If you have a tablet or laptop PC patients could use it take the survey independently, as long as you follow basic infection control procedures when passing the computer from patient to patient.
How do you score missing data?	Scale scores are 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.
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 (low, average, or high).
How do you use the KDQOL-36 template on the KDQOL website and what scores are worse than average?	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: <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

KDQOL Questions & Answers

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	5) Stats – provides mean, median, standard deviation scores (facility aggregate) on all scales 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/ .
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 latter is posted on the KDQOL website. The KDQOL-36 subset of items can be selected from the Spanish KDQOL 1.3 survey. You can enter the responses from the Spanish survey, but the Life Options KDQOL-36 Online site does not yet have a Spanish version of the patient score report. (This is coming in Spring of 2009 with KDQOL-COMplete.) You could use an interpreter or translator to share the scores and recommended actions 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 KDQOL-36 survey be reliable and valid?	Yes. See above.
Survey Documentation/Privacy/Confidentiality	
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 and whether those scores are average or better or worse than average.
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, a facility may have a policy that requires tracking scores. This would help the interdisciplinary team evaluate the success of an intervention in improving an individual's scores. It could also help a facility's QAPI committee to calculate the mean of aggregate scores to see whether the facility's patients are improving or not.
Where should the completed surveys be filed?	They should be kept in a locked private storage area.
If clinics are putting the KDQOL-36 results in the care plan, are target scores being listed (i.e.,	From the FAQ on www.gim.med.ucla.edu/kdqol/ <i>"We believe that having the scores in the medical</i>

KDQOL Questions & Answers

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physical component and mental component?)?	<i>record is an exciting possibility for maximizing the usefulness of health-related quality of life data in clinical practice."</i>
If surveys or scores are in the medical record, is it a breach of confidentiality to allow staff to read the patients' answers?	HIPAA does not prevent members of the healthcare team who need information for continuity of care to see pertinent medical records.
Survey Use in Interdisciplinary Plan of Care	
Is anyone addressing the KDQOL on the Care Plan or is it being used as a separate tool?	<p>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></p> <p>The Conditions for Coverage expect the KDQOL-36 to be used in interdisciplinary team care planning. It is essential that all team members understand the scores, the risk levels, and pertinent responses to direct the care they provide individually and jointly.</p> <p>The patient needs to be directly involved in care planning to assure that he/she agrees with the goals and is willing to do the interventions.</p>