

**NIDDK Liver Transplantation Database**  
**MANUAL OF OPERATIONS (MOOP) DEFINITION**

**FORM: QA (QUALITY OF LIFE: ADULTS)**

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Purpose: To document the adult patient's quality of life. The QA form will be sent annually to adult patients that are 16 years of age or greater on the anniversary of their initial liver transplant.

Person(s) Responsible: Patient upon receipt of the form.

Source(s) of Information: The patient, patient's next of kin, and/or a DCC interviewer.

General Instructions: The questions on the QA form are self-explanatory and the patient should be encouraged to fill out the form on his/her own. Help may be provided by the next of kin if the patient is too ill, confused, or unable to understand the questions because of educational, cultural or language difficulties. In these situations the next of kin can read the questions to the patient and record the answers, or supply the answers to the best of his/her knowledge. The name of the next of kin and relationship to the patient (spouse, child, sibling, parent, etc.) should be recorded on the form. The next of kin's name is strictly confidential and is not to be entered into the database.

Once the form is completed, the patient should return the form to the DCC or appropriate clinical center in the pre-addressed, postage-paid envelope that is provided. Upon receipt of the form, the LTD clinical center coordinator or DCC staff member should check that the form was completed correctly and completely.

If the patient does not want to answer a question, he/she should cross-out the question on the questionnaire. If the form has not been returned after two months, the clinical coordinator or a DCC staff member will make a follow-up call and this form may be administered by phone at that time.

The answers to all questions on the form should be kept strictly confidential and none revealed to the physicians or nurses responsible for the patient's care, or even to the principal investigator for the Liver Transplantation Database. This confidentiality should be maintained even for answers that might seem to have an impact on the patient's care such as a history of drinking alcohol or answers that indicate severe depression.

Eight QA forms were transcribed from the quality of life forms used by the Fujisawa FK506 study. These forms can be identified by the "Forms filled out" variable. Additional responses to 5 questions were incorporated in the LTD form to accurately transcribe data from the FK506 forms.

Completion Log:

- 1) Form Received Date – Record the date (month/day/year) that the form is received by mail, or the date that the interview is completed by phone.
- 2) The remaining completion log entries are for data entry use only.

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**Question 59**

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**Questions 60 through 63.10**

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**Question 29**

Karnofsky, D.A., Burchenal, J.H. (1949): In MacLeod, C.M. (ed.), Evaluation of Chemotherapeutic Agents, New York: Columbia University, pp. 191-205.

**Questions 31 through 58**

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**Questions 17 and 23**

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**Questions 18, 20, 21, and 24 through 27**

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