

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

FORM: QW (QUALITY OF LIFE: RETURN TO WORK: ADULTS)

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Purpose: To document the adult patient's post-transplant return to work experience. The QW form will be sent to patients who were adult at the time of their initial transplant, and have reached the 8th anniversary of that liver transplant.

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

If the form has not been returned to the DCC or appropriate clinical center within 2 months, the patient should be contacted and the form may be administered via phone interview. If the form has been returned partially completed, the patient should be contacted and the remaining questions completed via phone interview.

Source(s) of Information: The patient and the patient's next of kin.

General Instructions: 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.

Once the form is filled out, it should be returned to the DCC or appropriate clinical center in the pre-addressed, postage-paid envelope that is provided.

The answers to all questions on the form should be kept 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.

NOTE TO DATA ENTRY PERSONNEL: The first and last data entry PoP screens for the QW form request information that is not found on the paper form. Consult the clinical center coordinator for the following information.

- 1) Method of Data Collection – Data may be collected by patient mail-in, phone interview, or phone interview to complete the mail-in.
(1 = mail-in; 2 = phone interview; 3 = phone to complete mail-in).*
- 2) If any data was collected by phone, enter initials of the interviewer –
If any parts of the form are completed via phone interview, record the interviewer's three initials.*
- 3) If data was collected by phone/mail-in combination, record the questions completed by phone – If the form is returned incomplete and necessitates a phone interview to complete, record the question number for those items that were completed via the phone interview.*
- 4) Comments – If an item is incorrectly completed such that it cannot be coded, enter a "-4" for that item and record exactly how it was completed in the Comments section (last PoP screen). Precede each comment with the item number and an identifying keyword.*

- 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.

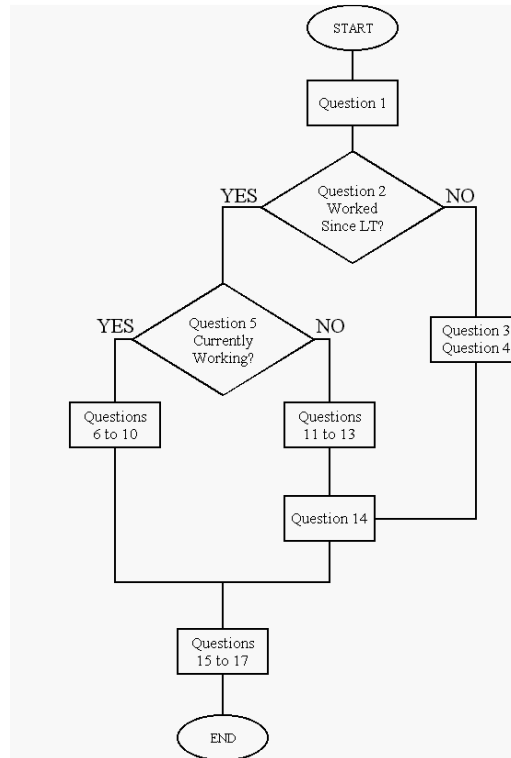
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EMPLOYMENT STATUS

The following diagram has been provided to facilitate understanding of the form completion path.



The code letters next to each question in the QW MOOP identify the group of individuals, based on employment status, that are to answer each question: A = Currently employed; B = Employed post-LT, but not currently; C = Never employed post-LT.

STATUS

- A, B, or C **1. WHAT WAS YOUR WORK ACTIVITY OR EMPLOYMENT STATUS PRIOR TO YOUR BECOMING ILL WITH LIVER DISEASE?**

Document the patient’s work activity or employment status prior to becoming ill with liver disease.

Completing Form: Check the employment status that best describes the patient’s work activity prior to becoming ill with liver disease. If the work activity or employment status is not listed, check “11. Other” and specify in the space provided. Note: specification is limited to 30 characters.

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STATUS

- A, B, or C **2. HAVE YOU WORKED FOR PAY AT ANY TIME SINCE YOUR FIRST TRANSPLANT?**

Document whether the patient has worked for pay at any time since receiving the first liver transplant.

Completing Form: Check “Yes” if the patient has worked for pay since the first liver transplant and skip to question 5. Check “No” if the patient has not worked for pay since the first liver transplant and continue with questions 3 and 4.

- C Only **3. WHICH OF THE FOLLOWING FACTORS PREVENTED YOUR RETURN TO WORK?**

Document the factor(s) that prevented the patient from returning to work following the first liver transplant.

Completing Form: Check the factor(s) that prevented the patient from returning to work following liver transplantation. If a factor that prevented the patient from returning to work is not listed, check “17. Other” and specify in the space provided. Note: specification is limited to 30 characters.

- C Only **4. WHICH OF THE FACTORS CHECKED ABOVE IS THE MOST IMPORTANT ONE THAT PREVENTED YOUR RETURN TO WORK?**

Of all the factors checked in question 3, document the factor that is the most important one that prevented the patient from returning to work following the first liver transplant.

Completing Form: Record the factor number checked in question 3 that is the most important one preventing the patient from returning to work. Skip to question 14.

- A Only **5. AFTER YOUR FIRST LIVER TRANSPLANT, HOW MANY MONTHS WAS IT UNTIL YOU STARTED TO WORK?**

Document in terms of months how long it was until the patient returned to work following the first liver transplant.

Completing Form: Record the number of months that passed before the patient returned to work following liver transplantation.

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STATUS

A or B

6. ARE YOU CURRENTLY WORKING FOR PAY?

If the patient has worked for pay following the first liver transplantation, document the patient's current employment status.

Completing Form: Check "Yes" if the patient is currently working for pay and continue with questions 7 to 10. Check "No" if the patient is not currently working for pay and skip to question 11.

A Only

7. WHAT IS YOUR CURRENT OCCUPATION?

Document the patient's current occupation and/or job title.

Completing Form: Record patient's current occupation and/or job title in the space provided. Note: occupation specification is limited to 30 characters.

A Only

8. CHECK THE CATEGORY THAT BEST DESCRIBES YOUR OCCUPATION:

Document the category that best describes the patient's current occupation.

Completing Form: Check the category that best describes the patient's current occupation. If none of the listed job description categories appropriately describe the occupation, check "7. Other" and specify in the space provided. Note: occupation description is limited to 30 characters.

A Only

9. ARE YOU WORKING:

Document whether the patient is currently employed full-time or part-time.

Completing Form: Check "full-time" if the patient is working 40 or more hours per week. Check "part-time" if the patient is working less than 40 hours per week.

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STATUS

A Only

- 10. IF EMPLOYED FULL- OR PART-TIME PRIOR TO YOUR BECOMING ILL WITH LIVER DISEASE, DID YOU RETURN TO WORK FOR YOUR PREVIOUS EMPLOYER?**

Document whether the patient returned to work for the same employer post-transplant that he/she worked for prior to becoming ill with liver disease.

Completing Form: Check “Yes” if the patient returned to work for his/her previous employer when first able to return to work post-transplant. Check “No” if the patient began working for a different employer when first able to return to work post-transplant. Check “Did not work...prior to becoming ill” if the patient is currently employed, but did not work prior to becoming ill with liver disease. Skip to question 15.

B Only

- 11. ARE YOU:**

Document the patient’s current unemployment status, given that the patient had been employed for pay at some point following the first liver transplant.

Completing Form: Check the item that best describes the patient’s current unemployment status. Note that items 1 and 2 are not applicable. If the current unemployment status is not listed, check “11. Other” and specify in the space provided. Note: specification is limited to 30 characters.

B Only

- 12. WHICH OF THE FOLLOWING FACTORS CAUSED YOU TO STOP WORKING?**

If the patient had worked for pay following his/her first liver transplant, document the factor(s) that contributed to the patient’s termination of employment.

Completing Form: Check the factor(s) that resulted in the patient’s termination of employment. If a factor that resulted in employment termination is not listed, check “17. Other” and specify in the space provided. Note: specification is limited to 30 characters.

B Only

- 13. WHICH OF THE FACTORS CHECKED ABOVE IS THE MOST IMPORTANT ONE THAT CAUSED YOU TO STOP WORKING?**

Of all the factors checked in question 12, document the factor that is the most important one that resulted in the patient’s termination of employment.

Completing Form: Record the factor number checked in question 12 that is the most important one that caused the patient to terminate employment.

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STATUS

B or C

14. DO YOU INTEND TO RETURN TO WORK?

Document whether the patient intends to return to work at any time in the future.

Completing Form: Check “Yes” if the patient intends to return to work. Check “No” if the patient does not intend to return to work. Check “Uncertain” if the patient is unsure as to whether he/she will return to work.

A, B, or C

15. WHAT HEALTH INSURANCE DO YOU HAVE AT THE PRESENT TIME?

Document the type(s) of health insurance currently held by the patient.

Completing Form: Check the type(s) of health insurance currently held by the patient. If the type of health insurance is not listed, check “7. Other” and specify in the space provided. Note: specification is limited to 30 characters.

A, B, or C

16. THIS FORM WAS FILLED OUT BY:

Document who filled out the form. If form was completed by the patient’s next of kin, then provide name and relationship to the patient. NOTE: the name of the next of kin is not to be entered into the computer database.

Completing Form: Check “Patient alone” if the form was completed by the patient. Check “Patient with assistance” if the form was read to the patient and/or if someone else recorded the patient’s answers to the questions (this includes phone interviews). Check “Next of kin” if the patient was unable to complete the form and a family member answered the questions for the patient. If the patient’s next of kin completed the form, record that person’s name and relationship to the patient. The next of kin’s name is strictly confidential and is not to be entered into the database. Note: relationship specification is limited to 30 characters.

A, B, or C

17. TODAY’S DATE

Document the date on which the form was completed.

Completing Form: Record the date (month/day/year) that this form was completed.