

**NHS BLOOD AND TRANSPLANT**

**LIVER ADVISORY GROUP**

**PROPOSED CHANGES TO ELECTIVE LIVER RECIPIENT  
REGISTRATION FORM**

**SUMMARY**

**BACKGROUND**

- 1 Changes are needed to be made to the Elective Liver Recipient Registration form in order to ensure we can collect new information necessary for the liver National Allocation Scheme. The current form is attached.

**PROPOSED CHANGES**

- 2 The form will need to capture the patient's preferences in terms of whether they would accept a DCD donor liver transplant, or a split liver transplant. This information will be used to avoid unnecessary offering but will mean that centres will need to keep this information up-to-date. A means of readily updating patient registration information will be provided.
- 3 It has also been noted that some of the liver disease codes are out of date and no longer in use. These include codes 443 and 445 which will be removed.

**LAG ACTIONS**

- 4 Members are asked to review the current form and discuss or feedback any other changes that may be required to support the new offering scheme or more generally.

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**NHSBT Statistics and Clinical Studies**

**May 2016**

# ***Elective Liver Recipient Registration***

## **Directions for completion**

- 1 This form should be completed for all patients who require an elective liver transplant.  
**Do not use this form to register patients with intestinal failure who require:**
  - liver only; or
  - bowel only; or
  - bowel & pancreas; or
  - liver, bowel & pancreas; or
  - multivisceral; or
  - modified multivisceral transplant
- 2 To register patients with intestinal failure, return a completed Intestinal Failure Transplant Recipient Registration (I-R) form to ODT Data Services at the address below.
- 3 **Do not use this form to register super-urgent patients.**  
To register super-urgent patients fax a completed Super-urgent Liver Recipient Registration (L-R-SU) form to the ODT Duty Office on the direct fax line: 0117 975 7599.
- 4 This is a single copy, 5-page form. When this form is complete, please staple the 5 pages together and send to ODT Data Services at the address below. Completed forms can be faxed to ODT Data Services using the direct fax line 0117 975 7570.
- 5 Please complete all sections of the form. **Failure to complete Sections 1-5 and 7, IN FULL, will result in patients not being registered onto the national liver transplant list until missing data items are made available.**

This form should be returned to

**ODT Data Services  
NHS Blood and Transplant  
Fox Den Road  
Stoke Gifford  
Bristol  
BS34 8RR**

Paper copies of this form can be obtained from ODT Data Services **Telephone 0117 975 7460**

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## LIVER DISEASE

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### Primary biliary cirrhosis

11 - Primary biliary cirrhosis

### Primary sclerosing cholangitis

14 - Primary sclerosing cholangitis

### Alcoholic liver disease

19 - Alcoholic liver disease

### Autoimmune and cryptogenic disease

12 - Autoimmune chronic active liver disease

17 - Cryptogenic cirrhosis

### Hepatitis C cirrhosis

24 - Hepatitis C cirrhosis

### Hepatitis B cirrhosis

13 - Hepatitis B cirrhosis

### Acute hepatic failure

27 - Acute hepatic failure - Budd-Chiari syndrome

30 - Acute hepatic failure - serologically indeterminate

34 - Acute hepatic failure - Wilson's disease

35 - Acute hepatic failure - HAV

36 - Acute hepatic failure - HBV

28 - Acute hepatic failure - other virus

37 - Acute hepatic failure - paracetamol hepatotoxicity

38 - Acute hepatic failure - other drug toxicity

39 - Acute hepatic failure - other, please specify

### Cancers

41 - Hepatocellular carcinoma - non-cirrhotic

42 - Hepatocellular carcinoma - cirrhotic

43 - Cholangiocarcinoma

44 - Hepatoblastoma

45 - Secondary hepatic malignancy

47 - Other primary hepatic malignancy, please specify

### Metabolic liver disease

15 - Alpha-1-antitrypsin deficiency

22 - Wilson's disease

26 - Non-alcoholic fatty liver disease

50 - Other metabolic liver disease, please specify

52 - Primary oxalosis

54 - Hyperlipidaemia

56 - Tyrosinaemia

57 - Familial amyloidosis

61 - Hereditary haemochromatosis

62 - Glycogen storage disease

### Other liver diseases

16 - Budd-Chiari syndrome (not code 27)

18 - Secondary biliary cirrhosis

20 - Biliary atresia

21 - Congenital hepatic fibrosis

23 - Congenital biliary disease

25 - Paediatric cholestatic liver disease, please specify

48 - Benign liver tumour

51 - Cystic fibrosis

53 - Graft versus host disease

55 - Trauma

60 - Polycystic liver disease

63 - Progressive familial intrahepatic cholestasis

64 - Neonatal haemochromatosis

66 - Hypercholesterolaemia

67 - Urea cycle disorder

68 - Crigler-Najjar syndrome

69 - Cholesterol ester storage disease

83 - Mitochondrial disease

84 - Alagilles syndrome

85 - Neonatal sclerosing cholangitis

86 - Other neonatal cholestasis

98 - Other, please specify

99 - Unknown

### Retransplantation

71 - Acute rejection

72 - Chronic rejection

73 - Primary non-function

75 - Non-thrombotic infarction

76 - Ductopenic rejection

77 - Recurrent disease

78 - Biliary complications

79 - Hepatic artery thrombosis

80 - Early graft dysfunction

81 - Acute vascular occlusion - venous

82 - Acute vascular occlusion - artery and venous

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## LIFESTYLE ACTIVITY SCORE

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1 - Able to carry out normal activity without restriction

2 - Only restricted in physically strenuous activity

3 - Can move freely. Capable of self care.

Unable to do any form of work

4 - Only capable of limited self care.

Confined mostly to bed or chair

5 - Completely reliant on nursing/medical care

7 - Aged five years or less

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## ENCEPHALOPATHY GRADE

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0 - Not present

1 - Compromised. Altered mood/behaviour.

Psychometric defects

2 - Drowsy. Inappropriate behaviour

3 - Stuporous but speaking and obeying simple commands.

Inarticulate speech. Marked confusion

4 - Coma. Cannot be aroused

# UK TRANSPLANT REGISTRY

Your centre code should be quoted on all pages

## Elective Liver Recipient Registration

CONSENT FOR USE OF PATIENT DATA		Section 1
Please indicate level of consent obtained Full = 1 Partial = 2 Refused = 3	If code 2, please specify data for which consent is not given (If required attach extra sheet including patient identifiers)	

RECIPIENT DETAILS		Section 2
Centre code <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Transplant centre <input type="text"/>	ODT Recipient number <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> (ODT to complete)
Recipient surname <input style="width: 100%;" type="text"/>	Group status Group 1 = 1 <input type="text"/> Group 2 = 2 <input type="text"/>	
Recipient forename(s) <input style="width: 100%;" type="text"/>	Date of birth <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
NHS number <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Sex Male = 1 <input type="text"/> Female = 2 <input type="text"/>	
Hospital number <input style="width: 100%;" type="text"/>	Blood group including, where known, subtypes of A ABO <input type="text"/> <input type="text"/> <input type="text"/> Rh <input type="text"/> <input type="text"/> Neg = N <input type="text"/> Pos = P <input type="text"/>	
Country of permanent residence <input style="width: 100%;" type="text"/>	Ethnic origin White = 1 <input type="text"/> Asian or Asian British = 2 <input type="text"/> Black or Black British = 3 <input type="text"/> Chinese/Oriental = 4 <input type="text"/> Mixed, please specify = 6 <input type="text"/> Other, please specify = 7 <input type="text"/> Unknown = 9 <input type="text"/>	
If UK or Republic of Ireland (ROI), permanent address <input style="width: 100%; height: 40px;" type="text"/>	If code 6 or 7, please specify <input style="width: 100%; height: 30px;" type="text"/>	
Postcode (IR99 9IR for ROI address) <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	VIROLOGY Negative = 1 <input type="text"/> Positive = 2 <input type="text"/> Not tested = 7 <input type="text"/> Unknown = 9 <input type="text"/>	
	CMV status <input type="text"/>	EBV (IgG) status <input type="text"/>
	HIV status <input type="text"/>	

REGISTRATION DETAILS		Section 3
Do you want this recipient to be entered on the waiting list as: ACTIVE or SUSPENDED? Active = A <input type="text"/> Suspended = S <input type="text"/>	Code (all) the recipient's liver disease(s) or reason for retransplantation in order of indication (See codes inside cover)	
Do you wish this recipient to be considered for a paediatric donor organ? No = 1 <input type="text"/> Yes = 2 <input type="text"/>	Indication (1) <input type="text"/> <input type="text"/> <input type="text"/> (2) <input type="text"/> <input type="text"/> <input type="text"/> (3) <input type="text"/> <input type="text"/> <input type="text"/>	
Is this part of a registration for a multi-organ transplant? No = 1 <input type="text"/> Yes = 2 <input type="text"/>	If code 13, is HDV present? No = 1 <input type="text"/> Yes = 2 <input type="text"/> Unknown = 9 <input type="text"/>	
If YES, please indicate other organs required and please complete the appropriate registration form(s) Kidney and/or pancreas No = 1 <input type="text"/> Yes = 2 <input type="text"/>	If code 41 or 42, is the tumour of fibrolamellar type? No = 1 <input type="text"/> Yes = 2 <input type="text"/> Unknown = 9 <input type="text"/>	
If YES, indicate renal transplant centre involved <input style="width: 100%; height: 30px;" type="text"/>	If code 25, 39, 47, 50 or 98, please specify <input style="width: 100%; height: 100px;" type="text"/>	
Heart and/or lung No = 1 <input type="text"/> Yes = 2 <input type="text"/>		
If YES, indicate cardi thoracic transplant centre involved <input style="width: 100%; height: 30px;" type="text"/>		
Number of previous liver transplants (from living and deceased donors) that this recipient has received (Unknown = 99) <input type="text"/> <input type="text"/>		

## UK TRANSPLANT REGISTRY

Your centre code should be quoted on all pages

### Elective Liver Recipient Registration

Recipient name

Centre code (ODT to complete)       Transplant centre  ODT Recipient number (ODT to complete)

#### REGISTRATION DETAILS continued

#### Section 3

##### PHYSICAL CHARACTERISTICS

Give details of the recipient, and if paediatric, those required of a potential donor

	Recipient	Donor minimum	Donor maximum
Height	<input type="text"/> <input type="text"/> <input type="text"/> cm	<input type="text"/> <input type="text"/> <input type="text"/> cm	<input type="text"/> <input type="text"/> <input type="text"/> cm
Weight	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> kg	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> kg	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> kg

#### CRITERIA FOR SELECTION ONTO THE TRANSPLANT LIST FOR ADULT (≥17) FIRST LIVER REGISTRATIONS ONLY

#### Section 4

(This section should not be completed for paediatric (<17) liver registrations or registrations for a re-transplant)

Please select ANY OR ALL of the following THREE set criteria and provide the corresponding details requested

##### 1) Chronic liver disease or failure

Yes = 2

If YES, is there an associated HCC? No = 1   
Yes = 2

IF YES, PLEASE COMPLETE CRITERIA 2 BELOW

Projected 1 year liver disease mortality without transplantation of > 9%, predicted by a UKELD score of 49 or greater.

Patients with alcoholic liver disease, past intravenous drug use or current methadone users must be assessed as recommended in prior Liver Advisory Group documents. Professional assessment of the risk of recurrence of at risk behaviour will be undertaken and either a contract signed by the patient or a letter sent from the transplanting centre stating the criteria on which transplantation is offered, the contents of which are agreed with the patient.

##### 2) Hepatocellular carcinoma (HCC)

Yes = 2

If YES,  
Number of tumours

##### All tumour(s) ≤ 5cms

No = 1   
Yes = 2

If YES,  
Maximum size of tumour(s)

Tumour 1   cm

Tumour 2   cm

Tumour 3   cm

Tumour 4   cm

Tumour 5   cm

##### Tumour >5 and ≤ 7cms

No = 1   
Yes = 2

If YES,  
Maximum dimensions   cm

Date diagnosed     2 0

Date of 6 month assessment     2 0

Maximum dimensions at 6 month assessment   cm

Radiological evidence of vascular invasion No = 1   
Yes = 2

Biopsy confirmation of tumour(s) No = 1   
Yes = 2

Tumour rupture No = 1   
Yes = 2

Maximum AFP level recorded       iu/ml

Radiological assessment should include both MDCT and MRI with size being assessed by the widest dimensions on either scan.

A tumour (for the purposes of counting numbers) will require to be identified as an arterialised focal abnormality with portal phase washout on MDCT or Gd enhanced MR. Other tumours are considered indeterminate.

Tumour rupture and an AFP >10,000 iu/ml are absolute contraindications to transplantation, as are extrahepatic spread and macroscopic vascular invasion.

The following are criteria for listing for transplantation:

- a single tumour ≤ 5cms diameter or
- up to 5 tumours all ≤ 3cms or
- single tumour >5cms and ≤ 7cms diameter where there has been no evidence of tumour progression (volume increase by <20%); no extrahepatic spread; no new nodule formation over a 6 month period. Locoregional therapy +/- chemotherapy may be given during that time. Their waiting list place may be considered from the time of their first staging scan.

Locoregional therapy should be considered for all transplant list cases.

Cases outwith current proposed selection criteria will not be selectable on to the transplant list after their tumour has been downsized by surgical or locoregional treatments.

# UK TRANSPLANT REGISTRY

## Elective Liver Recipient Registration

Recipient name

Centre code  
(ODT to complete)

Transplant  
centre

ODT Recipient number  
(ODT to complete)

### CRITERIA FOR SELECTION ONTO THE TRANSPLANT LIST FOR ADULT (≥17) FIRST LIVER REGISTRATIONS ONLY (continued)

Section 4

#### 3) A variant syndrome

If YES,

##### a) Diuretic resistant ascites

If YES,

Diuretics

Paracentesis

TIPS

Prior spontaneous bacterial  
peritonitis

Yes = 2 ☐

No = 1 ☐

Yes = 2 ☐

No = 1 ☐

Yes = 2 ☐

No = 1 ☐

Yes = 2 ☐

No = 1 ☐

Yes = 2 ☐

##### b) Hepatopulmonary syndrome

If YES,

Alveolar arterial oxygen gradient

mmHg

Calculated shunt fraction

%

No = 1 ☐

Yes = 2 ☐

##### c) Chronic hepatic encephalopathy

If YES,

Number of admissions in last year due  
to hepatic encephalopathy

No = 1 ☐

Yes = 2 ☐

##### d) Persistent and intractable pruritus

If YES, therapy tried

Cholestyramine

UDCA

Rifampicin

Ondansetron

Naltrexone

No = 1 ☐

Yes = 2 ☐

No = 1 ☐

Yes = 2 ☐

No = 1 ☐

Yes = 2 ☐

No = 1 ☐

Yes = 2 ☐

##### e) Familial amyloidosis

No = 1 ☐

Yes = 2 ☐

##### f) Primary hyperlipidaemia

No = 1 ☐

Yes = 2 ☐

##### g) Polycystic liver disease

No = 1 ☐

Yes = 2 ☐

##### h) Recurrent cholangitis

No = 1 ☐

Yes = 2 ☐

##### i) Other

No = 1 ☐

Yes = 2 ☐

If YES, please specify

Date of  
agreement

A variant syndrome in patients whose UKELD score is less than 49.

Ascites unresponsive to or intolerant of maximum diuretic dosage and non-responsive to TIPS or where TIPS deemed impossible or contraindicated.

Arterial PO<sub>2</sub> < 7.8, alveolar arterial oxygen gradient > 20 mmHg, calculated shunt fraction > 8% (brain uptake following TC macroaggregated albumen), pulmonary vascular dilatation documented by positive contrast enhanced transthoracic echo, in the absence of overt chronic lung disease.

Confirmed by EEG or trail making tests, with at least two admissions in one year due to exacerbations in encephalopathy, not manageable by standard therapy. Structural neurological disease must be excluded by appropriate imaging and, if necessary, psychometric testing.

Pruritus consequent on cholestatic liver disease, which is intractable after therapeutic trials. Record which drug therapy has been tried. Exclude psychiatric co-morbidity that might contribute to the itch. Lethargy is not an accepted primary indication for orthotopic liver transplantation.

Confirmed transthyretin gene mutation in the absence of significant debilitating cardiac involvement, or autonomic neuropathy.

Homozygous familial hypercholesterolaemia, absent LDL receptor expression and LDL receptor gene mutation.

Intractable symptom due to mass of liver or pain unresponsive to cystectomy, or severe complications secondary to portal hypertension.

Recurrent significant cholangitis not responsive to medical, surgical or endoscopic therapy.

Any other type of variant syndrome not included above, as agreed by a national selection panel.

# UK TRANSPLANT REGISTRY

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## Elective Liver Recipient Registration

Recipient name

Centre code (ODT to complete)       Transplant centre  ODT Recipient number (ODT to complete)

### INVESTIGATION RESULTS FOR ALL REGISTRATIONS

### Section 5

Haemoglobin	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> g/dl	Prothrombin time	<input type="text"/> <input type="text"/> <input type="text"/> seconds
White blood cells	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> x10 <sup>9</sup> /l	Serum bilirubin	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> μmol/l
Platelets	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> x10 <sup>9</sup> /l	Serum sodium	<input type="text"/> <input type="text"/> <input type="text"/> mmol/l
Serum urea	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> mmol/l	Serum potassium	<input type="text"/> <input type="text"/> <input type="text"/> mmol/l
Serum creatinine (not on dialysis)	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> μmol/l	Arterial PO <sub>2</sub>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> KPa
Serum albumin	<input type="text"/> <input type="text"/> <input type="text"/> g/l	AFP level	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> iu/ml
INR	<input type="text"/> <input type="text"/> <input type="text"/>		

### CLINICAL STATUS FOR ALL REGISTRATIONS

### Section 6

Lifestyle activity score (See codes inside cover) (Enter 7 for children aged 5 years or less)	<input type="text"/>	CARDIOVASCULAR DISEASE	
Patient location	Outpatient = 1 <input type="text"/> Ward = 2 <input type="text"/> ICU/HDU = 3 <input type="text"/>	Prior cardiac disease	No = 1 <input type="text"/> Yes = 2 <input type="text"/>
Ventilated	No = 1 <input type="text"/> Yes = 2 <input type="text"/>	Current angina	No = 1 <input type="text"/> Yes = 2 <input type="text"/>
Renal support	Haemodialysis = 1 <input type="text"/> Haemofiltration = 2 <input type="text"/> Not required = 3 <input type="text"/>	If YES, prior/current treatment	Drugs = 1 <input type="text"/> Stent = 2 <input type="text"/> CABG = 3 <input type="text"/> Other = 4 <input type="text"/>
Encephalopathy grade (See codes inside cover)	<input type="text"/>	Cerebrovascular disease	No = 1 <input type="text"/> Yes = 2 <input type="text"/>
Previous upper abdominal surgery	No = 1 <input type="text"/> Yes = 2 <input type="text"/>	Symptomatic peripheral vascular disease	No = 1 <input type="text"/> Yes = 2 <input type="text"/>
Oesophageal varices	Large = 1 <input type="text"/> Small = 2 <input type="text"/> Not present = 3 <input type="text"/> Unknown = 9 <input type="text"/>	Is the patient diabetic?	No = 1 <input type="text"/> Yes = 2 <input type="text"/>
Variceal haemorrhage	No previous variceal bleed = 1 <input type="text"/> Previous variceal bleed = 2 <input type="text"/>	If YES,	
If code 2, please indicate	No therapy = 1 <input type="text"/> Beta-blockade = 2 <input type="text"/> Endoscopic therapy = 3 <input type="text"/> Surgical shunt = 4 <input type="text"/> TIPS = 5 <input type="text"/>	Year of diagnosis	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Inotrope therapy	No = 1 <input type="text"/> Yes = 2 <input type="text"/>	Cause	Type I = 1 <input type="text"/> Type II = 2 <input type="text"/> Other (eg pancreatotomy) = 3 <input type="text"/>
If YES, please indicate type	Dopamine = 1 <input type="text"/> Adrenaline = 2 <input type="text"/> Noradrenaline = 3 <input type="text"/> Terlipressin = 4 <input type="text"/> Other = 5 <input type="text"/>	If code 3, please specify	<input type="text"/>
Current ascites	No = 1 <input type="text"/> Mild = 2 <input type="text"/> Moderate = 3 <input type="text"/> Severe = 4 <input type="text"/>	Treatment	Diet = 1 <input type="text"/> Tablets = 2 <input type="text"/> Insulin = 3 <input type="text"/>
Portal vein patency	Not patent = 1 <input type="text"/> Patent = 2 <input type="text"/>	Previous malignancy	No = 1 <input type="text"/> Yes, one = 2 <input type="text"/> Yes, multiple = 3 <input type="text"/> Unknown = 9 <input type="text"/>
Prior spontaneous bacterial peritonitis	No = 1 <input type="text"/> Yes = 2 <input type="text"/>	If YES, provide details of most relevant	
Hypertension	No = 1 <input type="text"/> Yes = 2 <input type="text"/>	Site of malignancy	<input type="text"/>
Opiate usage	Previous = 1 <input type="text"/> Current = 2 <input type="text"/> None = 3 <input type="text"/>	Type of malignancy	<input type="text"/>
		Diagnosis date (mm/yyyy)	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
		SMOKING	
		Pipe/cigars	No = 1 <input type="text"/> Yes = 2 <input type="text"/>
		Cigarettes	No = 1 <input type="text"/> Yes = 2 <input type="text"/> Ex-smoker = 3 <input type="text"/>
		If YES, number per day (Cigarettes only)	<input type="text"/> <input type="text"/>
		If EX-SMOKER, years since stop (To nearest year, 6 months = 1 year)	<input type="text"/> <input type="text"/>
		Total exposure in pack years (1 pack year = 20 cigarettes per day for 1 year)	<input type="text"/> <input type="text"/>

**UK TRANSPLANT REGISTRY**

Your centre code should be quoted on all pages

**Elective Liver Recipient Registration**

Recipient name

Centre code  
(ODT to complete)

Transplant  
centre

ODT Recipient number  
(ODT to complete)

**FORM COMPLETER DETAILS**

**Section 7**

Form completed by

Full name - please print

Position held

Contact telephone number

Date