

**NHS BLOOD AND TRANSPLANT**  
**ORGAN DONATION AND TRANSPLANTATION DIRECTORATE**  
**LIVER ADVISORY GROUP**

**PROVISION OF STANDARD DATA SETS FOR LIVER TRANSPLANT**

Through the organ and donation web site at:

<http://odt.nhs.uk/uk-transplant-registry/data/>

NHSBT makes available a limited data set containing outcome data and certain demographic and other factors to those who request it. This has always been regarded as a first step in making available fuller information on the outcomes of transplant recipients.

The Chair of LAG has asked for more detailed information to be provided on liver recipients. The intention is to reduce the workload created on NHSBT in reviewing and processing applications for national transplant data and moving towards a standardised data provision that addresses at least some of the data requirements of the transplant community.

In the course of our work, we use what we term a standard data set for each organ, which includes donor and recipient demographics, survival outcomes, and follow up data at 3 months, 1 and 5 years. The liver standard data set is attached (Appendix 1) and is proposed to be made available to applicants who request such data via our organ and donation web page.

This proposal has been developed by the Core Group of the LAG from an earlier version presented at the Advisory Group Chairs Committee (AGChC(14)25).

**ACTION**

Members of the LAG are asked to consider the liver data set in Appendix 1 and agree to data sharing as outlined above.

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**Principal Statistician – Statistics and Clinical Studies**  
**NHS Blood and Transplant**

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# APPENDIX I      Standard Liver Transplant Dataset

VARIABLE	DESCRIPTION	LEVEL
RECIP_ID	Anonymous recipient number	
TX_ID	Anonymous transplant number	
REG_ID	Anonymous registration number	
TX_DATE	Year of transplant	
REREG	Re-registered after transplant indicator	Yes No
REREG_DATE	Year of re-registration after transplant (if applicable)	
RE_TXD	Re-transplanted indicator	Yes No
NEXT_TX	Year of next transplant (if applicable)	
TX_TYPE	Type of transplant	Liver only Intestinal Failure Liver-Only Intestinal Failure Liver, Small Bowel & Pancreas Intestinal Failure Multi-visceral Liver & Kidney Liver, Kidney & Pancreas Liver, Heart & Lung Liver & Pancreas Liver & Heart Liver & Lung
MULTI_TX	Multi-organ transplant indicator	Liver only transplant Multiple organ transplant
SM_BOWEL	Liver and small bowel combined transplant indicator	No small bowel Liver and small bowel combined transplant
TX_METHOD	Transplant method	Orthotopic Missing Unknown
ORGAN	Lobe/segment of liver transplanted	Whole liver Left lobe Right lobe Left lateral segment Liver segment IV
ORG_TXD	Organ grafted as reported on the Liver Tx Record Form	Whole liver Reduced liver Split liver Auxiliary Missing Unknown
URGENT	Urgency status at registration	Elective Super-urgent

VARIABLE	DESCRIPTION	LEVEL
SU_FLAG	Super-urgent query indicator	Registered transplant No active record Transplanted whilst suspended Transplanted after transplant Transplanted after removal Transplanted after death reported
LIVER	Completeness of liver transplanted (note: there must be two recipients of one liver for it to be classed as split)	Whole Reduced Split
ALLTX_NO	Recipient transplant number	Counts all solid organ transplants
GRAFT_NO TXNATION	Number of liver transplant Nation of transplant centre: England, Scotland, RoI, Overseas	Counts liver transplants only
TXCOUNTRY	Country where transplant was performed: Overseas, RoI, UK	
DONOR_ID	Anonymous donor number	
DDATE	Month and year of donation	
DTYPE	Type of donor: DCD or DBD	
DGRP	Donor type group	Donor after brain death Donor after circulatory death Living (related, unrelated) Domino
DAGE	Donor age at donation	
DAGE_GRP	Donor paediatric/ adult indicator according to liver definition	Paediatric (<16) Adult (16 or over) Unknown
DBG	Donor blood group	Group O Group A Group B Group AB Missing
DCOD	Donor cause of death	
DCMV	Donor CMV test result	
DNATION	Nation of donor hospital: England, Scotland, RoI, Overseas	
DCOUNTRY	Country of donor hospital: Overseas, RoI, UK	
RAGE	Recipient age at transplant	
RAGE_GRP	Recipient paediatric/adult indicator according to liver definition	Paediatric (≤16) Adult (17 or over) Unknown

VARIABLE	DESCRIPTION	LEVEL
RPC2	Letters of first part of recipient's postcode	
RIMD	Recipient's 2010 IMD deprivation score based on postcode	
RRANK_IMD	Recipient's 2010 IMD deprivation ranking order, 1 being the most deprived	
RBG	Recipient blood group	Group O Group A Group B Group AB Missing
RWEIGHT	Recipient weight at registration (kg)	
RHEIGHT	Recipient height at registration (cm)	
RETHNIC	Recipient ethnicity group	
RCMV	CMV test result at registration	
RHCV	Most recent recipient HCV test result	
PLD	Best known primary liver disease Extracted from either (elective/su) registration or liver tx forms. Former trumps latter	
RCOD	Primary recipient cause of death	
RCOD2	Secondary recipient cause of death	
NHS_GRP	NHS group status	Group 1 Group 2 Not reported Unknown
ABOMATCH	Donor vs recipient blood group	Identical Compatible Incompatible
RCSPLD1	Primary liver disease at tx	
RCSPLD2	Secondary liver disease at tx	
RCSPLD3	Tertiary liver disease at tx	
RFAIL_GRADE	Recipient liver failure grading prior to tx	Hyperacute Acute Subacute Not acute
RLIFE	Recipient life style activity score prior to tx	
RIN_PAT	Recipient in patient status prior to tx	No Yes
RVENT	Recipient ventilation status prior	No

VARIABLE	DESCRIPTION	LEVEL
RREN_SUP	Recipient renal support status prior to tx	Yes Haemodialysis Filtration Not required
RASCITES	Recipient clinically detectable ascities status prior to tx	No Yes (8,9 missing codes)
RDIURETIC	Recipient diuretic therapy status prior to tx	No Yes (8,9 missing codes)
RENCEPH	Recipient encephalopathy grade prior to tx	Not encephalopathic Grade 1 Grade 2 Grade 3 Grade 4 (8,9 missing codes)
RAB_SURGERY	Recipient abdominal surgery indicator prior to tx	No Yes (8,9 missing codes)
RICP_MON	Recipient ICP monitor results prior to tx	Normal pressure Raised pressure Not used (8,9 missing codes)
ROES_VARICES	Recipient oesophageal varices prior to tx	No previous variceal bleed Previous variceal bleed Not present (8,9 missing codes)
ROES_SHUNT	Recipient shunt for varices (if present) prior to tx	No portosystemic shunt Surgical shunt TIPS (8,9 missing codes)
RPYREXIAL	Recipient pyrexial indicator prior to tx	No Yes (8,9 missing codes)
RSEPSIS	Recipient sepsis confirmed indicator prior to tx	No Yes (8,9 missing codes)
RSEPSIS_SITE	Recipient site of sepsis (if present) prior to tx	Sputum Blood Urine Ascities/drain fluid Wound Other (8,9 missing codes)
RHB	Recipient haemoglobin (gm/dl) prior to tx	
RWBC	Recipient white blood cells (x10 <sup>9</sup> /l) prior to tx	
RPLATELETS	Recipient platelets (x10 <sup>9</sup> /l) prior to tx	
RCREAT	Recipient creatinine (μmol/l) prior to tx	
RCREAT_CORR	Recipient creatinine (μmol/l) prior to tx after applying the Royal Free correction factor	
RALBUMIN	Recipient albumin (g/l) prior to tx	
RUREA	Recipient urea (mmol/l) prior to tx	

VARIABLE	DESCRIPTION	LEVEL
RINR	Recipient INR prior to tx	
RBILRUBIN	Recipient bilirubin ( $\mu\text{mol/l}$ ) prior to tx	
RSODIUM	Recipient sodium ( $\text{mmol/l}$ ) prior to tx	
UKELD	Recipient UK End-stage Liver Disease score prior to transplant for elective patients	
MELD	Recipient Model for End-stage Liver Disease score prior to transplant for elective patients	
RPOTASSIUM	Recipient potassium ( $\text{mmol/l}$ ) prior to tx	
RPH	Recipient pH prior to tx	
ROXYGEN	Recipient oxygen pressure (KPa) prior to tx	
RHBV_DNA	HBV DNA antigen result prior to tx	
RHBS_AG	HBs AG antigen result prior to tx	
RHBE_AG	HBe AG antigen result prior to tx	
RHCV_RNA	HCV-RNA (PCR) antigen result prior to tx	
RANTI_HBCLGM	Anti HBcIgM result prior to tx	
RANTI_HBS	Anti HBs result prior to tx	
RANTI_HBE	Anti HBe result prior to tx	
RANTI_HCV	Anti HCV result prior to tx	
RANTI_DELTA	Anti DELTA result prior to tx	
RANTI_CMV	Anti CMV result prior to tx	
RANTI_HSV	Anti HSV result prior to tx	
RANTI_HIV	Anti HIV result prior to tx	
PRES_FLUID	Preservation fluid used for organ	
ORG_APP	Donor organ appearance	Healthy Suboptimal (8,9 missing codes)
HEP_ARTERY	Hepatic artery appearance	Single Accessory (8,9 missing codes)
CIT	Cold ischaemia time (mins)	
VV_TIME	Veno-venous bypass time (hrs)	
REP_TIME	Operative reperfusion time (hrs)	
BA	Biliary anastomosis	No stent T-Tube Roux Stent (8,9 missing codes)
AA	Hepatic artery anastomosis	Single Multiple (8,9 missing codes)
RANTI_FIB	Indicator for anti-fibrinolytic therapy used	No Yes (8,9 missing codes)

VARIABLE	DESCRIPTION	LEVEL
IO_D	Indicator for intraoperative death	No Yes (8,9 missing codes)
IO_BLOOD	Intraoperative blood (units)	
IO_PLASMA	Intraoperative fresh frozen plasma (units)	
IO_PLATELETS	Intraoperative platelets (units)	
IO_CRYO	Intraoperative cryoprecipitate (units)	
PO_BLOOD	Postoperative blood (units)	
PO_PLASMA	Postoperative plasma (units)	
PO_PLATELETS	Postoperative platelets (units)	
PO_CRYO	Postoperative cryoprecipitate (units)	
COF	Cause of transplant failure	
LOST_FUP	Recipient lost to follow-up	No Yes (8 missing code)
FAILDATE	Month and year of graft failure	
TSURV	Transplant survival time (days)	
TCENS	Transplant censoring indicator	Censored Event (Graft failure or death)
GSURV	Graft survival time (days)	
GCENS	Graft censoring indicator	Censored Event (Graft failure only)
GSTATUS	Graft status of that particular graft (Note: if graft failed and patient died then GSTATUS will be 2)	Still alive, graft functioning Graft failed Death with a functioning graft Death only reported
LASTSTAT	Graft status of latest graft (Notes: If graft failed and patient died then LASTSTAT will be 2. If patient has had more than one graft this field will be the same for all grafts.)	Still alive, graft functioning Graft failed Death with a functioning graft Death only reported
LAST_GRAFT_NO	Graft number of latest graft	
PSURV	Patient survival time (days) (Note: populated for first grafts only but can include survival time following a subsequent liver transplant)	
PCENS	Patient censoring indicator (Note: populated for first grafts only)	Censored Event (Death of recipient)
FYR	First part of tx financial year	
FYR1	Second part of tx financial year	
FIN_YR	Full tx financial year	

VARIABLE	DESCRIPTION	LEVEL
<b><u>FOLLOW UP DATA AT 3 MONTHS, 1 AND 5 YEARS</u></b>		
TMF_LIFESTYLE	Lifestyle activity score at 3 month post transplant	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
TMF_REJECTION_EPISODES	Number of treated rejection episodes since transplant at 3 month form	
TMF_DAYS_VENTILATED	Number of days ventilated post-transplant	
TMF_DAYS_IN_ITU	Number of days in ITU post-transplant	
TMF_RENAL_STATUSES	Renal status post-transplant	1=No or minor renal impairment, 2=Required transient renal filtration, 3=Short-term dialysis, 4=Long-term dialysis
TMF_HEPATIC_ART_THROMBOSIS	Complications hepatic artery thrombosis	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_PORTAL_VEIN_THROMBOSIS	Complications portal vein thrombosis	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_IVC	Complications IVC/hepatic vein occlusion	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_HAEMORRHAGE	Complications haemorrhage requiring reoperation	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_BILIARY_TRACT_LEAK	Complications biliary tract leaks	1=No leak, 2=Leak not treated, 3=Leak requiring reoperation, 4=Other radiological intervention
TMF_BILIARY_TRACT_STRICTURE	Complications biliary tract stricture	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_BILIARY_STRICTURE_TREATMENT	Complications biliary tract stricture treatment	1=Reoperated, 2=Balloon dilatation, 3=Stenting
TMF_CMV_INFECTION	Post-operative CMV infection	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_FUNGAL_INFECTION	Post-operative fungal infection	1=No, 2=Yes, 8=Not reported, 9=Unknown

VARIABLE	DESCRIPTION	LEVEL
TMF_SPUTUM_SEPSIS	Post-operative sputum sepsis	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_BLOOD_SEPSIS	Post-operative blood sepsis	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_URINE_SEPSIS	Post-operative urine sepsis	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_ASCITIES_SEPSIS	Post-operative ascities sepsis	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_WOUND_SEPSIS	Post-operative wound sepsis	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_OTHER_SEPSIS	Post-operative other sepsis	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_CYCLOSPORIN	Immunosuppression at 3 months: Cyclosporin A	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_AZATHIOPRINE	Immunosuppression at 3 months: Azathioprine	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_MYCOPHENOLATE	Immunosuppression at 3 months: Mycophenolate mofetil	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_PREDNISOLONE	Immunosuppression at 3 months: Prednisolone	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_FK506	Immunosuppression at 3 months: FK 506	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_IMMUNO_DRUG_OTHER	Immunosuppression at 3 months: Other	1=No, 2=Yes, 8=Not reported, 9=Unknown
TMF_IMMUNO_DRUG_OTHER_TEXT	Immunosuppression at 3 months: Other text	
AF1Y_LIFESTYLE	Lifestyle activity score at 1 year post transplant	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
AF1Y_DAYS_INPATIENT	Total number of days as an inpatient at 1 year	
AF1Y_PROTOCOL	Number of readmissions at 1 year	
AF1Y_PROTOCOL	Number of readmissions if protocol was the primary reason for readmittance	
AF1Y_ACUTE_REJECTION	Number of re-admissions if acute rejection was the primary reason for re-admittance	

VARIABLE	DESCRIPTION	LEVEL
AF1Y_CHRONIC_REJECTION	Number of re-admissions if chronic rejection was the primary reason for re-admittance	
AF1Y_BILIARY_COMPLICATION	Number of re-admissions if biliary complications was the primary reason for re-admittance	
AF1Y_VASCULAR_COMPLICATION	Number of re-admissions if vascular complications was the primary reason for re-admittance	
AF1Y_DISEASE_RECURRENCE	Number of re-admissions if disease recurrence was the primary reason for re-admittance	
AF1Y_INFECTION	Number of re-admissions if infection was the primary reason for re-admittance	
AF1Y_READMIT_OTHER	Number of re-admissions if other was the primary reason for re-admittance	
AF1Y_BILIRUBIN	Bilirubin at 1 year ( $\mu\text{mol/l}$ )	
AF1Y_ALKALINE_PHOSPHATASE	Alk phosphatase at 1 year (IU/L)	
AF1Y_ALT_SGOT	ALT/SGOT at 1 year (IU/L)	
AF1Y_AST_SGPT	AST/SGPT at 1 year (IU/L)	
AF1Y_BLOOD_UREA	Blood urea at 1 year (mmol/l)	
AF1Y_DYSFUNCTION	Is renal dysfunction present at 1 year	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF1Y_TUMOUR	Tumour been detected at 1 year	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF1Y_CYCLOSPORIN	Immunosuppression at 1 year: Cyclosporin A	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF1Y_FK506	Immunosuppression at 1 year: FK 506	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF1Y_AZATHIOPRINE	Immunosuppression at 1 year: Azathioprine	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF1Y_MYCOPHENOLATE	Immunosuppression at 1 year: Mycophenolate mofetil	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF1Y_PREDNISOLONE	Immunosuppression at 1 year: Prednisolone	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF1Y_IMMUNOSUPPRESSION_OTHER	Immunosuppression at 1 year: Other	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF1Y_IMMUNOSUPPRESSION_OTHER_TEXT	Immunosuppression at 1 year: Other text	

VARIABLE	DESCRIPTION	LEVEL
AF5Y_LIFESTYLE	Lifestyle activity score at 5 years post transplant	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
AF5Y_DAYS_INPATIENT	Total number of days as an inpatient across 5 years	
AF5Y_READMISSIONS	Number of re-admissions across 5 years	
AF5Y_PROTOCOL	Total number of readmissions if protocol was the primary reason for readmittance across 5 years	
AF5Y_ACUTE_REJECTION	Total number of re-admissions if acute rejection was the primary reason for readmittance across 5 years	
AF5Y_CHRONIC_REJECTION	Total number of re-admissions if chronic rejection was the primary reason for readmittance across 5 years	
AF5Y_BILIARY_COMPLICATION	Total number of re-admissions if biliary complications was the primary reason for re-admittance across 5 years	
AF5Y_VASCULAR_COMPLICATION	Total number of re-admissions if vascular complications was the primary reason for re-admittance across 5 years	
AF5Y_DISEASE_RECURRENCE	Total number of readmissions if disease recurrence was the primary reason for re-admittance across 5 years	
AF5Y_INFECTION	Total number of re-admissions if infection was the primary reason for re-admittance across 5 years	
AF5Y_READMIT_OTHER	Total number of re-admissions if other was the primary reason for readmittance across 5 years	
AF5Y_BILIRUBIN	Bilirubin at 5 years ( $\mu\text{mol/l}$ )	
AF5Y_ALK_PHOSPHATASE	Alk phosphatase at 5 years (IU/L)	

VARIABLE	DESCRIPTION	LEVEL
AF5Y_ALT_SGOT	ALT/SGOT at 5 years (IU/L)	
AF5Y_AST_SGPT	AST/SGPT at 5 years (IU/L)	
AF5Y_BLOOD_UREA	Blood urea at 5 years (mmol/l)	
AF5Y_DYSFUNCTION	Is renal dysfunction present at 5 years	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF5Y_TUMOUR	Tumour been detected at 5 years	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF5Y_CYCLOSPORIN	Immunosuppression at 5 years: Cyclosporin A	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF5Y_FK506	Immunosuppression at 5 years: FK 506	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF5Y_AZATHIOPRINE	Immunosuppression at 5 years: Azathioprine	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF5Y_MYCOPHENOLATE	Immunosuppression at 5 years: Mycophenolate mofetil	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF5Y_PREDNISOLONE	Immunosuppression at 5 years: Prednisolone	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF5Y_IMMUNODRUG_OTHER	Immunosuppression at 5 years: Other	1=No, 2=Yes, 8=Not reported, 9=Unknown
AF5Y_IMMUNODRUG_OTHER_TEXT	Immunosuppression at 5 years: Other text	