LDLT Registry
Donor follow up
&
monitoring

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Previous Situation

- No National Registry for Live Liver Donors
- Individual transplant centres organising their own donor follow up in accordance with BTS Recommendations:
  - Life-long follow-up, either locally or at the transplant centre.
  - Overseas donors, not entitled to NHS follow-up, must be given advice before returning to their country of origin.
- Potential donors who are unable to proceed to donation must be appropriately followed up and referred for further investigation and management as required.

Follow up Recommendations

- Current practise in most centres is 4 weeks, with 3 and 6 months in primary care, annual review by the transplant centre for up to 2 years following donation
- Early follow-up to assess wound healing, monitoring of liver function, check psychological status
- By three months, it is anticipated that the donor will have made a full recovery and returned to normal activities.
- Long term annual follow up provides an opportunity for specific clinical review as well as a general health and wellbeing check, including psychosocial aspects.
- European Organ Donation Directive (EUODD) requirement since Aug'12 to collect annual life-long follow-up data on all living organ donors – can present a logistical issue with overseas donors
- Best practice requires the offer of life-long follow-up for all donors, with submission of data to NHSBT at specified time points for the UK Living Donor Registry.
- Appreciated that not all donors wish to return for regular review, but anecdotal experience from the living donor kidney programme suggests that many welcome it.

UK TRANSPLANT REGISTRY

Living Liver Donor Pre- and Post-

Retrieval centre

DONOR DETAILS

Donor surname

Donor forename(s)

Donor to participate in recognition scheme

Please record permanent address

Postcode *(IR99 9IR for ROI address, OS99 9OS for overseas address)*

INFORMATION REQUIRED BY HUMAN TISSUE ACT WITH THE QUALITY AND SAFETY OF ORGANS INTE

Donor case number (Hospital number)

Relationship of donor to recipient *(See codes inside cover)*

Independent Assessor ID

Date/time donor surgery commenced

Liver retrieved — Left lobe = 41, Right lobe = 42, Left lateral segment = 46 — 4

If retrieved liver not transplanted in intended recipie

Reason *(See codes inside cover)*

Organ outcome *(See codes inside cover)*

Please record the batch numbers of **all** perfusion fluid

Perfusion fluid *(See codes inside cover)*	Batch number(s)

RECIPIENT DETAILS

Please ensure Elective Liver Recipient Registration Form

Recipient surname

Recipient forename(s)

UK TRANSPLANT REGISTRY

Please NHS Bl P

Living Liver Donor Pre- and Post-opera

PRE-OPERATIVE DONOR ASSESSMENT

Serum haemoglobin *(Most recent)* g/dl

Serum creatinine *(Most recent)* µmol/l

Serum albumin *(Most recent)* g/dl

Serum bilirubin *(Most recent)* µmol/l

Aspartate aminotransferase (AST) *(Most recent)* iu/l

Serum alkaline phosphatase *(Most recent)* iu/l

GFR method — Measured = 1, Estimated/calculated = 2, Not available = 3

If code 1 or 2, please state GFR *(To nearest ml)* ml/min Measu estima

Creatinine clearance measured — No = 1, Yes = 2

If YES, please state creatinine clearance ml/min Measu

Blood pressure (sitting) *(To nearest 2mm)* /

Is ECG normal? — No = 1, Yes = 2 — If NO, please comment

Additional cardiac investigations — Please specify type

Any significant co-morbid condition (eg cardiac or respiratory disease) — Please specify. If nc

Any regular drug therapy — Please specify

SMOKING Pipe/cigars — No = 1, Yes = 2 — Cigarettes — Ne Ye Ex-smoke

DONOR SCREENING

Negative = 1, Positive = 2, Test result awaited = 6, Not tested = 7, Unknown = 9

HBsAg HBcAb

EBV HTL

FRM4150/3 (Previous document reference L-LIV-DI)

UK TRANSPLANT REGISTRY

Living Liver Donor Pre- and Post-o

OPERATIVE AND POST-OPERATIVE DONOR DETAILS

Hepatic artery (HA) anatomy with graft

If LEFT LATERAL SEGMENT retrieved, specify

If LEFT LOBE retrieved, specify

If RIGHT LOBE retrieved, specify

Bile duct with graft

If LEFT LATERAL SEGMENT retrieved, specify

Left hepatic duct

Separate segmental ducts — On Two p

If LEFT LOBE retrieved, specify

Left hepatic duct

Segment IV duct — Conserved with Sa

Separate segmental ducts — On Two p

If RIGHT LOBE retrieved, specify

Right hepatic duct

Anterior and posterior sectoral ducts — On Two p

Hepatic vein (HV) anatomy with graft

If LEFT LATERAL SEGMENT retrieved, specify

Left HV

Segmental veins — On Two p

If LEFT LOBE retrieved, specify

Left and middle HVs — On Two p

If RIGHT LOBE retrieved, specify

UK TRANSPLANT REGISTRY

Please ensure the copy returned to NHS Blood and Transplant is legible
PLEASE PRESS FIRMLY

NHS Blood and Transplant

Living Liver Donor Pre- and Post-operative Assessment

HTA Form A Number

OPERATIVE AND POST-OPERATIVE DONOR DETAILS continued — Section 5

DVT prophylaxis — No = 1, Yes = 2

If YES, method of prophylaxis — Subcutaneous heparin — No = 1, Yes = 2 — TED stockings — No = 1, Yes = 2

Other — No = 1, Yes = 2 — If YES, please specify

Weight of graft g

PERI- OR POST-OPERATIVE COMPLICATIONS DURING INDEX ADMISSION

Operative haemorrhage (requiring blood transfusion) — No = 1, Yes = 2

Requirement for re-operation — No = 1, Yes = 2 — If YES, please specify — Requirement for re-operation details

Pneumonia — No = 1, Yes = 2

Wound infection — No = 1, Yes = 2

DVT — No = 1, Yes = 2 — Other complications details

Pulmonary thromboembolism — No = 1, Yes = 2

Bile leak — No = 1, Yes = 2

Jaundice — No = 1, Yes = 2

Maximum bilirubin µmol/l

Other complications — No = 1, Yes = 2 — If YES, please specify

Date of discharge 20

DONOR HEPATECTOMY TEAM

Operating surgeon — Consultant = 1, Specialist Registrar = 2, Other = 5 — If code 5, please specify

Anaesthetist — Consultant = 1, Specialist Registrar = 2, Other = 5 — If code 5, please specify

Most senior surgeon scrubbed — Consultant = 1, Specialist Registrar = 2, Other = 5 — If code 5, please specify

FORM COMPLETER DETAILS — Section 6

Form completed by *(If not retrieving surgeon)* — Full name - please print

Position held *(If not retrieving surgeon)*

Contact telephone number

Date 20

Recommended changes to FRM4150 Form (Living Live Donor Pre- & Post-operative Assessment)

- Additions:
  - INR
  - Type of donation: directed, directed altruistic or non-directed altruistic
  - Alteration to information on the graft
  - surgical data record to include number of arteries, veins and ducts in the graft (image predicted and actual)
  - Volumetrics and steatosis estimate
  - Future proofed with option of laparoscopic or robotic donor hepatectomy
  - Anaesthetic summary: blood products, use of VVB &/or RRT and inotropic requirement at point of transfer to ICU/HDU
- Removals:
  - DVT prophylaxis as this is standard in national guidelines

New Time Points for Data Collection

- ***7-day form -*** donor work-up, retrieval information, and regulatory elements. Meets the same requirements as an HTA-A form, with enough information for NHSBT to set up the donor record and register the transplant.
- ***3-month form –*** remaining data that isn't possible to return at day 7 e.g. discharge date and return to work date. Aim that this will mimic other pathways for deceased donation, whereby the recipient will have a 3-month follow-up form.
- ***12-month/annual form -*** data points collected annually thereafter.

Data for New Forms

DONOR DETAILS

Retrieval Centre
Centre Code
ODT Donor Number
Donor Surname
Donor Forename
Donor DoB
Donor NHS Number
Donor Sex
Donor ABO
Donor RH
Donor Ethnic Group
Donor Height
Donor Weight
Donor Body mass index
Donor to participate in the recognition scheme?
Donor Address
Donor Postcode

INFORMATION REQUIRED BY HUMAN TISSUE ACT (2004), HUMAN TISSUE (SCOTLAND) ACT (2006) AND FOR COMPLIANCE WITH THE QUALITY AND SAFETY OF ORGANS INTENDED FOR TRANSPLANTATION REGULATIONS (2012)

Donor case (hospital) number
Donor relationship to recipient
Type of donation (Directed/directed altruistic/non-directed altruistic)
Independent Assessor ID
HTA Reference number
Date/Time donor surgery commended

Liver retrieved?
(Left lobe / Right lobe / Left lateral segment)

If retrieved liver was not transplanted into the intended recipient, please state:
Reason
Organ outcome

Prefusion fluid type	Batch Number

To be completed and signed by the retrieving surgeon
Operation completed by (Full name)
Appointment held at (Establishment)
Position held
Signature

RECIPIENT DETAILS

Recipient Surname
Recipient Forename
Recipient Date of birth
Recipient sex

PRE-OPERATIVE DONOR ASSESSMENT

Serum haemoglobin (most recent)
Measured on

Serum creatinine (most recent)
Measured on

Serum albumin (most recent)
Measured on

Serum bilirubin (most recent)
Measured on

Aspartate aminotransferase (AST) (most recent)
Measured on

Serum alkaline phosphatase (most recent)
Measured on

INR (most recent)
Measured on

GFR Method (Measured, Estimated/calculated, Not available)
If measured or estimated/calculated
GFR
Date measured/estimated on
Corrected for body surface area?

Creatine clearance measured?
If yes
If yes, please state creatinine clearance
Measured on
Corrected for body surface area?

Blood pressure (sitting)
Is ECG normal?
Additional cardiac investigations?
Any significant co-morbid condition? (e.g cardiac or respiratory)
Any regular drug therapy
What is the donors ASA status
Has donor completed SF36 form? (Yes/no)

SMOKING

Pipes/cigars
Cigarettes
If yes
Number/day
If ex-smoker
Years since stop

DONOR SCREENING

HBsAg
HBcAb
HCV
HIV
CMV
EBV
HTLV
Toxo
Syphilis

OPERATIVE AND POST-OPERATIVE DONOR DETAILS

Hepatic artery (HA) anatomy with graft
If LEFT LATERAL SEGMENT retrieved, specify
Left HA from common HA
Left HA from common HA + accessory left HA from left gastric artery (GA)
Fully replaced left HA from left GA

Separate segment II/III vessels
One patch or two patches

If LEFT LOBE retrieved, specify
Left HA from common HA
Left HA from common HA + accessory left HA from left GA
Fully replaced left HA from left GA

Separate segment IV vesse
Conserved or sacrific

If RIGHT LOBE retrieved, specify
Right HA from common HA
Fully replaced right HA from SMA
Right HA from common HA + accessory right HA from SMA

Arteries with right lobe
One patch or two pathces

Bile duct with graft
If LEFT LATERAL SEGMENT retrieved, specify
Left hepatic duct (Yes/No)
Separate segmental ducts (One patch or two patches)

If LEFT LOBE retrieved, spec
Left hepatic duct (Yes/N
Segment IV duct (Conserved with donor or sacrifice
Separate segmental ducts (One patch or two patche

If RIGHT LOBE retrieved, specify
Right hepatic duct (Yes/No)
Anterior and posterior sectoral ducts (One patch or two patches)

Hepatic vein (HV) anatomy with graft
If LEFT LATERAL SEGMENT retrieved, specify
Left HV (Yes/No)
Segmental veins (One patch or two patches)

If LEFT LOBE retrieved, specify
Left and middle HVs (One patch or two patches)

If RIGHT LOBE retrieved, specify
Right HV alone
Right HV + reconstructed segment V vein
Right HV + reconstructed segment VIII vein
Right HV + reconstructed segments V and VIII veins
Right HV + reconstructed inferior right HV - one patch
Right HV + reconstructed inferior right HV - two patches

VOLUMETRICS

Predicted weight (g)
Actual weight (g)
Predicted volume (ml)
Actual volume (ml)
Estimated percentage steatosis of graft

HEPATECTOMY

Open (Yes/no)
Lapatoscopic (Yes/no)
Robotic donor hepatectomy (yes/no)

ANATOMY

Image predicted
Number of arteries
Number of veins
Number of ducts in the graft
Actual
Number of arteries
Number of veins
Number of ducts in the graft

ANAESTHETIC SUMMARY

Blood products used
PRBc
Cell Sav
FF
Platele
Cryoprecipita

Venous Bypass used (Yes/no)
Renal replacement therapy (Yes/no)
Inotropic requirement at point of transfer to ICT/HDU

PERI- OR POST-OPERATIVE COMPLICATIONS DURING INDEX ADMISSION

Operative haemorrhage (requiring blood transfusion) (Yes/no)
Requirement for re-operation (Yes/no)
If yes, please specify
Pneumonia (Yes/no)
Wound infection (Yes/no)
Pulmonary thromboembolism (Yes/no)
Bile leak (Yes/no)
Jaundice (Yes/no)
Maximum bilirubin (Yes/no)
Other complications (Yes/no)
If yes, please spec
What is the donors ASA status
Has donor completed SF36 form? (Yes/no)
Date of discharge

DONOR HEPATECTOMY TEAM

Operating surgeon (Consultant, Specialist Registrar or other)
Anaesthetist (Consultant, Specialist Registrar or other)
Most senior surgeon scrubbed (Consultant, Specialist Registrar or other)

TRANSFER OR LOSS OF DONOR TO FOLLOW-UP

Transferred for follow-up?
If yes
Name and address of centre handling follow-up

Lost to follow-up
If yes
Please supply reason

FOLLOW-UP DETAILS

Has the donor died
If yes
Date of death
Cause of death

Date of last review

Synthetic liver function
Bilirubin
INR
Albumin

Serum creatinine
Measured on

Haemoglobin
Measured on

GFR
Measured on

Blood pressure (sitting)
Measured on

Weight

Any new medications prescribed since last reported follow up?
If yes
Please specify

Any new medical issues since last reported follow-up

Any complications related to surgery
Diarrhoea
Refulx
Nausea
Abdominal pain
Incisional Hernia
Biliary complications
Other

Has the donor returned to previous levels of general activity?
If yes
Give the time after donation when previous levels attained (months)

Has the donor returned to work?
If yes
Give the time after donation when they returnted to work (months)
If no
Reason

What is the donors ASA status
Has donor completed SF36 form?

Data Collection

- Number of options discussed that were felt to have minimal difference to those collecting and sending the data
  - Living path – purpose built platform but doesn't yet have the IT input required
  - Paper forms onto APEX database – user friendly but risk of error with data transcription
  - Microsoft forms – lengthy process for clinician input, no IT input needed
  - Paper forms onto Excel spreadsheet – again risk of transcription error and data integrity, harder to perform statistical analysis

- FWTG/LDLT Project Board discussed and opted for paper forms onto APEX database at NHSBT

International Live Liver Donor Registry

- Many more data points than we plan to collect
- A useful resource

Global variation in living donor liver transplantation practices impacts donor and recipient short-term outcomes: Initial insights from the International LDLT Registry.

- Recent publication in August in AJT highlighting disparities in practice and how HDI effects short-term outcomes.
- Numerous influences on variation in practise – geographical, cultural and economic.
- Evaulated the association between short term outcomes and the Human Development Index (HDI).
- Data from September 2023 to June 2024 prospectively from 70 centers in 26 countries, 1575 pairs.
- Donors from very high HDI regions had a higher prevalence of comorbidities (17.4%) than those from low HDI regions (1.2%; $P < .001$) but a lower complication rate (9.8% v 21.9% for low HDI, $P < 0.001$).
- Multivariable analysis indicated significantly reduced short-term postoperative donor morbidity in very high HDI regions (odds ratio, 0.32; 95% confidence interval, 0.23-0.44; $P < .001$).
- Conclude a need for global cooperation to standardize practices and enhance care quality to ensure equitable access to liver transplantation worldwide.

Global variation in living donor liver transplantation practices impacts donor and recipient short-term outcomes: Initial insights from the International LDLT Registry. Chief Investigators, et al.
AJT, Volume 25, Issue 8, 1735 - 1745

Questions?