

Registration process for liver indications requiring additional waiting time

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Summary of changes

Useful information

Additional details regarding patient offered through hepatoblastoma tier and offering sequence.

Patients with Hepatoblastoma section:

- Changed responsibility for checking that the recipient has been correctly registered
- Added requirement for hepatoblastoma patients requiring liver and intestinal organs require approval from MCTAG
- Responsibility for determining points moved to ODT Hub: Information Services
- Steps clarified of who must be contacted following additional points being added

Prioritised paediatric patient section

- Clarification added depending on which organs are being listed for
- Clarification added for registration updates for liver and intestinal recipients
- Changed responsibility for checking that the recipient has been correctly registered
- Responsibility for determining points moved to ODT Hub: Information Services
- Steps clarified of who must be contacted following additional points being added

Acute on Chronic Liver Failure (ACLF) section

- Updated current approval list
- Changed responsibility for checking that the recipient has been correctly registered
- Responsibility for determining points required (if any) moved to ODT Hub: Information Services
- Steps clarified of who must be contacted following the registration being updated

Neuroendocrine tumours section

- Updated registration guidance
- Added steps to be taken to calculate additional waiting time points
- Steps clarified of who must be contacted following additional points being added

Unresectable Colorectal Metastases section

- Added steps to be taken to calculate additional waiting time points
- Steps clarified of who must be contacted following additional points being added

Severe or very severe Hepatopulmonary Syndrome patients' section

- Updated registration guidance
- Added steps to be taken to calculate additional waiting time points
- Steps clarified of who must be contacted following additional points being added

Intrahepatic Cholangiocarcinoma section

- Updated registration guidance
- Added steps to be taken to calculate additional waiting time points
- Steps clarified of who must be contacted following additional points being added

Useful Information

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1. Policies and documents

- **POL195** - Liver Transplantation: Selection Criteria and Recipient Registration
- **SOP5844** – Hub Operations Team Manager (HOTM) Processes - Hub Operations
- **FRM4332** – Elective liver recipient registration form

2. Definitions

- **Adult liver recipient:** aged 17 years or over at time of registration and does not fall within small adult criteria.
- **Small adult liver recipient:** aged 17 years or over at time of registration with a body weight of 40kg or less and dual-listing option specified by centre on the registration form or via submission of sequential data forms.
- **Paediatric liver recipient:** aged less than 17 years at time of registration and does not fall within large paediatric criteria.
- **Large paediatric liver recipient:** aged less than 17 years at time of registration with a body weight of 40kg or more and dual-listing option specified by centre on the registration form or via submission of sequential data forms.

3. Hepatoblastoma tier

- The following indications are offered through the hepatoblastoma tier
 - Patients with hepatoblastoma
 - Paediatric patients where prioritisation has been formally agreed
 - Patients with Acute on Chronic Liver Failure (ACLF)
- It has been agreed that patients should appear in the above offering sequence and additional points (as specified in the relevant sections below) are added by NHSBT to ensure the correct offering sequence.

Patients with Hepatoblastoma

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1. Introduction

Liver only patients with hepatoblastoma do not need approval from any of the other transplant centres. Note that patients with hepatoblastoma requiring liver and intestinal organs should be reviewed and agreed by the Chairs of the Multivisceral and Composite Tissues Advisory Group (MCTAG) and Liver Advisory Group (LAG) prior to registration and will require a PDV.

2. Registration Process

Transplant centres wishing to register a liver or liver and intestinal patient with hepatoblastoma should complete the Elective Liver Recipient Registration Form (FRM4332) and submit the form to NHS Blood and Transplant on ODT Online.

Transplant centres should subsequently email ODT Hub: Information Services (ODTRegistrationTeamManagers@nhsbt.nhs.uk) after submitting the form to inform ODT Hub: Information Services that they have registered a patient with hepatoblastoma. Confirmation from the Chairs of MCTAG and LAG should also be forwarded for liver and intestinal patients with hepatoblastoma.

Note that these emails will be actioned by both ODT Hub: Information Services and Statistics & Clinical Research during working hours (10am - 4pm Monday - Friday).

Also, note that a report is automatically produced every day showing the patients that are active on the elective transplant list with hepatoblastoma as the primary indication. Therefore, transplant centres should be aware that although the patient will appear on the active elective waiting list once the registration form is committed, they may not appear in the correct position on the hepatoblastoma tier until additional waiting time is added and there may be a delay if transplant centres do not email ODT Hub: Information Services.

ODT Hub: Information Services will check the recipient's registration to ensure that they have been correctly registered into as a hepatoblastoma recipient.

3. Additional Waiting Time

If it has been confirmed that the patient has hepatoblastoma, ODT Hub: Information Services will add an additional 9000 waiting time points, the waiting time will be automatically updated when the waiting time batch-job is next run:

- 00:05 – All organ waiting time is recalculated
- 10:00 – Liver and Intestinal waiting time is re-calculated
- 14:00 – Liver and Intestinal waiting time is re-calculated
- 18:00 – Liver and Intestinal waiting time is re-calculated

After the additional points have been added to the recipient the following should be emailed:

- Senior Statistician (Liver)
 - o To check that registration is correct, and that points have been applied correctly
- Statistical.Enquiries@nhsbt.nhs.uk
 - o To escalate if the Senior Statistician is not available
- odthuboperations.shiftmanagers@nhsbt.nhs.uk
 - o To inform Hub-Operations that a recipient has been added to the hepatoblastoma tier.

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A representative from Statistics and Clinical Research will check and confirm the correct additional waiting time has been added.

Once confirmation has been received the recipient centre should be informed that the changes have been applied.

If the incorrect additional waiting time is added, the lead from Statistics and Clinical Research will notify ODT Hub Information Services and confirm the correct additional waiting time. The Higher/Senior Information Office will subsequently notify the [Operational Lead](#) or Operational Manager.

If the additional waiting time added is higher than requested, the Higher/Senior Information Officer will contact the database team and request urgent amendment through both [ServiceNow](#) and a phone call.

If the additional waiting time added is lower than requested, the Higher/Senior Information Officer will correct and email the Statistical lead and Statistical Enquiries for confirmation.

The additional waiting time will be removed, as per **SOP5844**, once the transplant centre confirms the patient has received a liver transplant.

If it is confirmed that the patient doesn't have hepatoblastoma but is either a prioritised paediatric patient or has ACLF then the relevant sections should be followed.

Prioritised Paediatric Patients

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1. Introduction

Weekly teleconferences were established in April 2020 involving adult and paediatric representation from all 7 UK liver transplant centres and NHS England to discuss and maintain a national liver transplant service during COVID-19. Requests were received from all three paediatric centres to either formally or informally prioritise individual paediatric patients who are clinically deteriorating but do not meet the super-urgent criteria.

Informal prioritisation allows a paediatric centre with support of one or both of the other paediatric centres to seek prioritisation of a specific recipient and to receive offers of organs made to another paediatric centre for that informally prioritised recipient. It should be noted that transplant centres maintain the responsibility to ask ODT Hub Operations to offer to the transplant centre where the patient is registered when offered organs. The patients position on the transplant list will not be changed.

Formal prioritisation of paediatric recipients requires agreement of all three paediatric centres. If unanimously agreed, paediatric patients formally prioritised would be registered in the hepatoblastoma tier **and offered livers after patients with hepatoblastoma**.

Note that this is for paediatric patients aged 16 years or under.

2. Approval

Requests to formally prioritise paediatric patients who are clinically deteriorating will be managed and overseen by the requesting transplant centre who will provide the following with information required

- Agreed representatives from the other UK paediatric transplant centres
- Chair and Deputy Chair of the National Appeals Panel
- Head of Service Delivery - ODT Hub
- Lead Statistician for Liver Transplantation

The request should include patient identifiable data (e.g., hospital number, NHS number, date of birth, initials), age, weight and ODT recipient identification number (if applicable). **Centres must include details of whether they would consider blood group incompatible offers, the liver lobes they would consider (e.g. left lateral segment or whole liver) and organs required.** The process may take longer for blood group incompatible offers as this will currently need to be undertaken under a risk assessment.

It is anticipated that a decision should be made within 72 hours.

Liver only patients require approval from:

- Written approval from the Chair of LAG
- Written approval from the two other paediatric centres (Leeds/Birmingham/Kings)
 - Potentially an adult centre if the recipient is a large paediatric **and require anything over a left lateral segment**

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Liver and intestinal patients require approval from:

- Written approval from the Chairs of LAG and MCTAG
- Written approval from the two other paediatric centres (Leeds/Birmingham/Kings)
 - Potentially an adult centre if the recipient is a large paediatric

Once agreed, the registration (including amendment) process below should be followed within working hours Monday to Friday. *Please note that it can take up to 12 hours for this to be actioned.*

3. Registration

Transplant centres wishing to register a prioritised paediatric patient should complete the Elective Liver Recipient Registration Form (**FRM4332**) with the following indications and submit the form to NHS Blood and Transplant on ODT Online.

Liver only:

- 444 (hepatoblastoma) as primary indication
- True primary disease as secondary indication
- 498 (Other, please specify) as tertiary indication with "PRIORITISED PAEDIATRIC PATIENT" in the free text

Liver and intestinal:

- 444 (hepatoblastoma) as primary indication
- True primary disease as secondary indication
- 498 (Other, please specify) as tertiary indication with "PRIORITISED LIVER AND INTESTINAL PAEDIATRIC PATIENT" in the free text

Please note, liver and intestinal patients will need to be included in a PDV to specify the organs required

Transplant centres should subsequently email ODT Hub: Information Services (ODTRegistrationTeamManagers@nhsbt.nhs.uk) after submitting the form to inform ODT Hub: Information Services that they have registered a prioritised paediatric patient *along with the agreement from the other centres.*

Note that these emails will be actioned by both ODT Hub: Information Services and Statistics & Clinical Research during working hours (10am - 4pm Monday - Friday).

Also, note that a report is automatically produced every day showing the patients that are active on the elective transplant list with hepatoblastoma as the primary indication. Therefore, transplant centres should be aware that although the patient will appear on the active elective waiting list once the registration form is committed, they may not appear in the correct position on the hepatoblastoma tier until additional waiting time is added and there may be a delay if transplant centres do not email ODT Hub: Information Services.

ODT Hub: Information Services will check the recipient's registration to ensure that they have been correctly registered into following the above criteria.

The process above should be followed for both new patients and patients already registered on the liver transplant list.

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4. Additional Waiting Time

If it has been confirmed that the patient is a prioritised paediatric patient, ODT Hub: Information Services will add an additional 5000 waiting time points, the waiting time will be automatically updated when the waiting time batch-job is next run:

- 00:05 – All organ waiting time is recalculated
- 10:00 – Liver and Intestinal waiting time is re-calculated
- 14:00 – Liver and Intestinal waiting time is re-calculated
- 18:00 – Liver and Intestinal waiting time is re-calculated

After the additional points have been added to the recipient the following should be emailed:

- Senior Statistician (Liver)
 - o To check that registration is correct, and that points have been applied correctly
- Statistical.Enquiries@nhsbt.nhs.uk
 - o To escalate if the Senior Statistician is not available
- odthuboperations.shiftmanagers@nhsbt.nhs.uk
 - o To inform Hub-Operations that a recipient has been added to the prioritised paediatric tier.

A representative from Statistics and Clinical Research will check and confirm the correct additional waiting time has been added.

Once confirmation has been received the recipient centre should be informed that the changes have been applied.

If the incorrect additional waiting time is added, the lead from Statistics and Clinical Research will notify ODT Hub Information Services and confirm the correct additional waiting time. The Higher/Senior Information Office will subsequently notify the [Operational Lead](#) or Operational Manager.

If the additional waiting time added is higher than requested, the Higher/Senior Information Officer will contact the database team and request urgent amendment through both ServiceNow and a phone call.

If the additional waiting time added is lower than requested, the Higher/Senior Information Officer will correct and email the [Senior Statistician \(Liver\)](#) and [Statistical Enquiries](#)

The additional waiting time will be removed, as per **SOP5844**, once the transplant centre confirms the patient has received a liver transplant.

If it is confirmed that the patient is not a prioritised paediatric patient but is either a patient with hepatoblastoma or ACLF then the [relevant sections](#) should be followed.

Acute on Chronic Liver Failure (ACLF)

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1. Introduction

Fixed Term Working Unit was established by LAG to examine liver transplantation in critically ill patients with cirrhosis (ACLF). A report was presented at the November 2019 LAG meeting and recommended that a new tier should be added to the offering sequence after paediatric offering but before the adult elective stage. This requires an IT change which has been raised.

Feedback and concern was received from transplant centres when a transplant centre submitted a super-urgent appeal for an ACLF patient. It was agreed at the weekly centre director telecon and at LAG that, prior to the IT change, ACLF patients should be offered in the hepatoblastoma tier.

It was also agreed that a super-urgent appeal was inappropriate for ACLF patients.

Note that this is for adult patients

The inclusion and exclusion criteria are:

Inclusion criteria for consideration under the ACLF process include:

- Requirement for care in ICU or HDU setting
- Cirrhotic Chronic Liver Disease
- ACLF with 28-day survival <50%, likely grade of 3 or higher

Exclusion Criteria include:

- Age >60 years
- Active bacterial or fungal sepsis
- Multi-organ failure overwhelming or with adverse trajectory
- Excessive comorbidity
- Frailty likely to preclude rehabilitation

2. Approval

Requests to prioritise ACLF patients who are clinically deteriorating will be managed and overseen by the requesting transplant centre who will provide the following with information required:

- Chair of FTWU (Will Bernal)
- Chair and Deputy Chair of the National Appeals Panel
- Head of Service Delivery - ODT Hub
- Lead Statistician for Liver Transplantation

The request should include patient identifiable data (e.g., hospital number, NHS number, date of birth, initials), age, weight and ODT recipient identification number (if applicable).

It is anticipated that a decision should be made within 24 hours.

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Majority approval is required from the following panel (a minimum of two approvals should be received where appropriate):

- The Chair of LAG
- Deputy Chair of LAG
- FTWG Lead
- Nominated consultant

It is noted that clinicians on both the panel and the nominating centre may wish to refrain from formally reviewing.

Once agreed, the registration (including amendment) process below should be followed within working hours Monday to Friday.

3. Registration Process

Transplant centres wishing to register an ACLF patient should complete the Elective Liver Recipient Registration Form (**FRM4332**) with the following indications and submit the form to NHS Blood and Transplant on ODT Online.

- 444 (hepatoblastoma) as primary indication
- True primary disease as secondary indication
- 498 (Other, please specify) as tertiary indication with "ACLF PATIENT" in the free text box

It has been agreed that ACLF patients should not receive split liver offers or multi-organ offers (e.g. liver/kidney offers). Transplant centres should therefore record No to whether the patient would like to receive an offer from a donor meeting splitting criteria on either the elective registration form or a new sequential update form.

Transplant centres should also remove the patient from the other organ list (please see section 4.6 in POL195 for further information).

Transplant centres should subsequently email ODT Hub: Information Services (ODTRegistrationTeamManagers@nhsbt.nhs.uk) after submitting the form to inform ODT Hub: Information Services that they have registered an ACLF patient *along with the agreement from the approval panel and the supplemental ACLF data form*.

Note that these emails will be actioned by both ODT Hub: Information Services and Statistics & Clinical Research during working hours (10am - 4pm Monday - Friday) **and it should be noted that this may take up to 12 hours**.

Also, note that a report is automatically produced every day showing the patients that are active on the elective transplant list with hepatoblastoma as the primary indication. Therefore, transplant centres should be aware that although the patient will appear on the active elective waiting list once the registration form is committed, they may not appear in the correct position on the hepatoblastoma tier until additional waiting time is added and there may be a delay if transplant centres do not email ODT Hub: Information Services.

The process above should be followed for both new patients and patients already registered on the liver transplant list.

ODT Hub: Information Services will check the recipient's registration to ensure that they have been correctly registered into following the above criteria.

Follow-up information additional to the standard post-transplant dataset will be required from centres for recipients transplanted through the ACLF tier.

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4. Additional Waiting Time

If it has been confirmed that the patient is an ACLF patient no waiting time points are to be added,

The following should be emailed:

- Senior Statistician (Liver)
 - o To check that registration is correct, and that points appear correctly
- Statistical.Enquiries@nhsbt.nhs.uk
 - o To escalate if the Senior Statistician is not available
- odthuboperations.shiftmanagers@nhsbt.nhs.uk
 - o To inform Hub-Operations that a recipient has been added to the ACLF tier.

A representative from Statistics and Clinical Research will check and confirm the waiting time appears correctly.

Once confirmation has been received the recipient centre should be informed that the changes have been applied.

it is confirmed that the patient is not an ACLF patient but is either a patient with hepatoblastoma or a prioritised paediatric patient, then the relevant section should be followed

Neuroendocrine tumours

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1. Introduction

Appendix B of POL195 (Liver Transplantation: Selection Criteria and Recipient Registration) details the inclusion and exclusion criteria for the neuroendocrine tumour (NET) service evaluation.

2. Approval

The National NET Board will review all suitable patients referred and determine suitability for the liver transplant pathway. Once agreed, these patients **do not** require approval from the National Appeals Panel or LAG Chair.

3. Registration

Transplant centres wishing to register a NET patient should complete the Elective Liver Recipient Registration Form (**FRM4332**) with the following information and submit the form to NHS Blood and Transplant on ODT Online.

- 498 (other please specify) as primary indication with "NEUROENDOCRINE TUMOUR (NET) PATIENT" in the free text
- Variant syndrome=Yes
- Other variant syndrome=Yes
- Date of agreement to be date agreed by National NET Board

UKELD does not need to be examined as other variant syndrome are offered through the variant syndrome pathway regardless of UKELD.

Transplant centres should subsequently email ODT Hub: Information Services (ODTRegistrationTeamManagers@nhsbt.nhs.uk) after submitting the form to inform ODT Hub: Information Services that they have registered a NET patient *along with the agreement from the national NET Board*.

Note that these emails will be actioned by both ODT Hub: Information Services and Statistics & Clinical Research during working hours (10am - 4pm Monday - Friday).

Also, note that a report is automatically produced every day showing the patients that are active on the elective transplant list with **one of the new cancer indications** as the primary indication. Therefore, transplant centres should be aware that although the patient will appear on the active elective waiting list once the registration form is committed, they may not appear in the correct position on the variant syndrome until additional waiting time is added and there may be a delay if transplant centres do not email ODT Hub: Information Services.

ODT Hub: Information Services will then contact Statistical Enquiries (statistical.enquiries@nhsbt.nhs.uk) and the Lead Statistician for Liver Transplantation to confirm the patient registration.

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4. Additional Waiting Time

It has been agreed that NET patients should receive a named patient offer within 6 months of listing. Therefore once confirmed, a Lead from Statistics & Clinical Research will email ODT Hub: Information Services to confirm, based on recipient blood group and weight the additional waiting days that should be added.

Additional time is calculated in [Additional time for HPS and new service evaluations.sas](#) which is stored in F:\Stats & Audit\Shared\Liver\Allocation\Additional time.

Running instructions:

- Open the SAS program
- Enter the recip_id identified in the daily batchjob or email (if centre emails)
- Enter 1 for net, crc, cca, shps or vshps as appropriate (leave the four as 0)
- Run the whole program
- Open wtime3a dataset and if extra variable is greater than 0 email ODTRegistrationTeamManagers@nhsbt.nhs.uk asking for the additional waiting time specified in extra to be added for the specific recip_id e.g. "please can we add AAAA extra additional waiting days for recip_id ZZZZZ (registration_id XXXXX)."

ODT Hub: Information Services will confirm receipt of the email and add the additional waiting time. The waiting time will be automatically updated when the waiting time batch-job is next run:

- 00:05 – All organ waiting time is recalculated
- 10:00 – Liver and Intestinal waiting time is re-calculated
- 14:00 – Liver and Intestinal waiting time is re-calculated
- 18:00 – Liver and Intestinal waiting time is re-calculated

After the additional points have been added to the recipient the following should be emailed:

- Senior Statistician (Liver)
 - o To check that registration is correct, and that points have been applied correctly
- Statistical.Enquiries@nhsbt.nhs.uk
 - o To escalate if the Senior Statistician is not available
- odthuboperations.shiftmanagers@nhsbt.nhs.uk
 - o To inform Hub-Operations that a recipient has been added to the Neuroendocrine tumours tier.

A representative from Statistics and Clinical Research will check and confirm the correct additional waiting time has been added.

Once confirmation has been received the recipient centre should be informed that the changes have been applied.

If the incorrect additional waiting time is added, the lead from Statistics and Clinical Research will notify ODT Hub Information Services and confirm the correct additional waiting time. The Higher/Senior Information Office will subsequently notify the [Operational Lead](#) or Operational Manager.

If the additional waiting time added is higher than requested, the Higher/Senior Information Officer will contact the database team and request urgent amendment through both service now and a phone call.

If the additional waiting time added is lower than requested, the Higher/Senior Information Officer will correct and email the Statistical lead for confirmation.

The additional waiting time will be removed, as per **SOP5844**, once the transplant centre confirms the patient has received a liver transplant.

Unresectable Colorectal Metastases

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1. Introduction

Appendix C of POL195 (Liver Transplantation: Selection Criteria and Recipient Registration) details the inclusion and exclusion criteria for the Colorectal (CRC) metastases service evaluation.

2. Approval

Individual transplant centres will review all suitable patients referred and determine suitability for the liver transplant pathway. These patients **do not** require approval from the National Appeals Panel or LAG Chair.

3. Registration

Transplant centres wishing to register a CRC Mets patient should complete the Elective Liver Recipient Registration Form (**FRM4332**) with the following information and submit the form to NHS Blood and Transplant on ODT Online.

- 498 (other please specify) as primary indication with "COLORECTAL (CRC) METASTASES PATIENT" in the free text
- Variant syndrome=Yes
- Other variant syndrome=Yes
- Date of agreement to be date registered

UKELD does not need to be examined as other variant syndrome are offered through the variant syndrome pathway regardless of UKELD

Transplant centres should subsequently email ODT Hub: Information Services (ODTRegistrationTeamManagers@nhsbt.nhs.uk) after submitting the form to inform ODT Hub: Information Services that they have registered a CRC Mets patient.

Note that these emails will be actioned by both ODT Hub: Information Services and Statistics & Clinical Research during working hours (10am - 4pm Monday - Friday).

Also, note that a report is automatically produced every day showing the patients that are active on the elective transplant list with **one of the new cancer indications** as the primary indication. Therefore, transplant centres should be aware that although the patient will appear on the active elective waiting list once the registration form is committed, they may not appear in the correct position on the variant syndrome until additional waiting time is added and there may be a delay if transplant centres do not email ODT Hub: Information Services.

ODT Hub: Information Services will then contact Statistical Enquiries (statistical.enquiries@nhsbt.nhs.uk) and the Lead Statistician for Liver Transplantation to confirm the patient registration.

4. Additional Waiting Time

It has been agreed that CRC Mets patients should receive a named patient offer within 3 months of listing. Therefore once confirmed, a Lead from Statistics & Clinical Research will email ODT Hub: Information Services to confirm, based on recipient blood group and weight the additional waiting days that should be added.

Additional time is calculated in [Additional time for HPS and new service evaluations.sas](#) which is stored in F:\Stats & Audit\Shared\Liver\Allocation\Additional time.

Running instructions:

- Open the SAS program
- Enter the recip_id identified in the daily batchjob or email (if centre emails)
- Enter 1 for net, crc, cca, shps or vshps as appropriate (leave the four as 0)
- Run the whole program
- Open wtime3a dataset and if extra variable is greater than 0 email ODTRegistrationTeamManagers@nhsbt.nhs.uk asking for the additional waiting time specified in extra to be added for the specific recip_id e.g. "please can we add AAAA extra additional waiting days for recip_id ZZZZZ (registration_id XXXXX)."

ODT Hub: Information Services will confirm receipt of the email and add the additional waiting time. The waiting time will be automatically updated when the waiting time batch-job is next run:

- 00:05 – All organ waiting time is recalculated
- 10:00 – Liver and Intestinal waiting time is re-calculated
- 14:00 – Liver and Intestinal waiting time is re-calculated
- 18:00 – Liver and Intestinal waiting time is re-calculated

After the additional points have been added to the recipient the following should be emailed:

- Senior Statistician (Liver)
 - o To check that registration is correct, and that points have been applied correctly
- Statistical.Enquiries@nhsbt.nhs.uk
 - o To escalate if the Senior Statistician is not available
- odthuboperations.shiftmanagers@nhsbt.nhs.uk
 - o To inform Hub-Operations that a recipient has been added to the Unresectable Colorectal Metastases tier.

A representative from Statistics and Clinical Research will check and confirm the correct additional waiting time has been added.

Once confirmation has been received the recipient centre should be informed that the changes have been applied.

If the incorrect additional waiting time is added, the lead from Statistics and Clinical Research will notify ODT Hub Information Services and confirm the correct additional waiting time. The Higher/Senior Information Office will subsequently notify the [Operational Lead](#) or Operational Manager.

If the additional waiting time added is higher than requested, the Higher/Senior Information Officer will contact the database team and request urgent amendment through both service now and a phone call.

If the additional waiting time added is lower than requested, the Higher/Senior Information Officer will correct and email the Statistical lead for confirmation.

The additional waiting time will be removed, as per **SOP5844**, once the transplant centre confirms the patient has received a liver transplant.

Severe or very severe Hepatopulmonary Syndrome patients

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1. Introduction

LAG(20)40 details the findings and recommendations of the Hepatopulmonary syndrome waiting list prioritisation Fixed term working unit. The FTWU recommend that ideally all severe-very severe HPS patients (PaO₂ on air <8 kPa) are transplanted within 1-year of listing. The FTWU also recommended that ideally all very severe HPS patients (PaO₂ on air <7 kPa) are transplanted within 3 months of listing.

2. Approval

Requests to prioritise patients with severe or very severe hepatopulmonary syndrome patients who are clinically deteriorating will be managed and overseen by the requesting transplant centre who will provide the following with information required:

- Chair and Deputy Chair of the National Appeals Panel
- Head of Service Delivery - ODT Hub
- Lead Statistician for Liver Transplantation

It is anticipated that a decision should be made within 24 hours.

Please note that this includes patients not currently on the list as well as patients on the list (regardless of pathway).

Once agreed, the registration (including amendment) process below should be followed within working hours Monday to Friday.

3. Registration

Transplant centres wishing to register a patient with either severe or very severe HPS **who is not currently on the list** should complete the Elective Liver Recipient Registration Form (FRM4332) with the following information and submit the form to NHS Blood and Transplant on ODT Online.

- Variant syndrome=Yes
- Hepatopulmonary syndrome=Yes

Transplant centres **wishing to move a currently registered patient with either severe or very severe HPS from the CLD/HCC pathway** should update the status to 23 (suspended pending transition) and then complete a new Elective Liver Recipient Registration Form (FRM4332) with the following information and submit the form to NHS Blood and Transplant on ODT Online.

- Variant syndrome=Yes
- Hepatopulmonary syndrome=Yes

Transplant centres should subsequently email ODT Hub: Information Services (ODTRegistrationTeamManagers@nhsbt.nhs.uk) after submitting the form to inform ODT Hub: Information Services that they have registered a patient along with the agreement from the LAG Chair.

Transplant centres should also email ODT Hub: Information Services (ODTRegistrationTeamManagers@nhsbt.nhs.uk) if they have a patient **currently registered on the Variant syndrome pathway with HPS who is deteriorating to severe or very severe**.

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Note that these emails will be actioned by both ODT Hub: Information Services and Statistics & Clinical Research during working hours (10am - 4pm Monday - Friday).

ODT Hub: Information Services will then contact Statistical Enquiries (statistical.enquiries@nhsbt.nhs.uk) and the Lead Statistician for Liver Transplantation to confirm either the patient registration or update.

The agreed offering pathway for patients with non-severe HPS is dependent on UKELD with patients with a UKELD of 49 or above offered through the Chronic Liver Disease pathway and not the variant syndrome pathway. The Lead Statistician for Liver Transplantation will review the patients actual UKELD and a dummy sequential update may need to be submitted with a UKELD less than 49 recorded so that patients with severe or very severe HPS are offered through the variant syndrome pathway.

If UKELD \geq 49

- Obtain the relevant registration_id from liver_reg_elective or recipient_status_history for the recip_id required.
- Obtain the data from liver_reg_investigation for the registration_id required.
- Extract the data into Excel
- Take a copy of the actual data and keep the latest data row
- Ensure investigation_type=2
- Change the investigation_date to date/time examined
- Null assessment_id and created_date (this will automatically be created when uploaded)
- Change the sodium value in the UKELD calculator to obtain a UKELD of 48 or less.
- Update the Excel document and save in year specific (e.g. 2023) folder in J:\DataServices_Stats\Data Error\Attachments
- Raise a database amendment request asking for it to be done asap as it affects offering pathway in Service Now
- Email database team to inform them that a new database amendment request has been submitted.

(See J:\DataServices_Stats\Data Error\Attachments\2022 for examples)

4. Additional Waiting Time

It has been agreed that patients with severe and very severe HPS should receive a named patient offer within 12 and 3 months of listing respectively.

Therefore once confirmed, a Lead from Statistics & Clinical Research will email ODT Hub: Information Services to confirm, based on recipient blood group and weight the additional waiting days that should be added.

Additional time is calculated in Additional time for HPS and new service evaluations.sas which is stored in F:\Stats & Audit\Shared\Liver\Allocation\Additional time.

Running instructions:

- Open the SAS program
- Enter the recip_id identified in the daily batchjob or email (if centre emails)
- Enter 1 for net, crc, cca, shps or vshps as appropriate (leave the four as 0)
- Run the whole program
- Open wtime3a dataset and if extra variable is greater than 0 email ODTRegistrationTeamManagers@nhsbt.nhs.uk asking for the additional waiting time specified in extra to be added for the specific recip_id e.g. "please can we add AAAA extra additional waiting days for recip_id ZZZZZ (registration_id XXXXX)."

Please note that patients already on the list will either be given additional waiting time or continue with their accrued waiting time (whichever higher) but not both.

SOP5907/5 – Registration process for liver Indications requiring additional waiting time



Blood and Transplant

Copy No:

Effective date: 18/09/2023

ODT Hub: Information Services will confirm receipt of the email and add the additional waiting time. The waiting time will be automatically updated when the waiting time batch-job is next run:

- 00:05 – All organ waiting time is recalculated
- 10:00 – Liver and Intestinal waiting time is re-calculated
- 14:00 – Liver and Intestinal waiting time is re-calculated
- 18:00 – Liver and Intestinal waiting time is re-calculated

After the additional points have been added to the recipient the following should be emailed:

- Senior Statistician (Liver)
 - o To check that registration is correct, and that points have been applied correctly
- Statistical.Enquiries@nhsbt.nhs.uk
 - o To escalate if the Senior Statistician is not available
- odthuboperations.shiftmanagers@nhsbt.nhs.uk
 - o To inform Hub-Operations that a recipient has been added to Severe or very severe Hepatopulmonary Syndrome patients tier.

A representative from Statistics and Clinical Research will check and confirm the correct additional waiting time has been added.

Once confirmation has been received the recipient centre should be informed that the changes have been applied.

If the incorrect additional waiting time is added, the lead from Statistics and Clinical Research will notify ODT Hub Information Services and confirm the correct additional waiting time. The Higher/Senior Information Office will subsequently notify the **Operational Lead** or Operational Manager.

If the additional waiting time added is higher than requested, the Higher/Senior Information Officer will contact the database team and request urgent amendment through both service now and a phone call.

If the additional waiting time added is lower than requested, the Higher/Senior Information Officer will correct and email the Statistical lead for confirmation.

The additional waiting time will be removed, as per **SOP5844**, once the transplant centre confirms the patient has received a liver transplant.

Intrahepatic Cholangiocarcinoma

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1. Introduction

Appendix D of POL195 (Liver Transplantation: Selection Criteria and Recipient Registration) details the inclusion and exclusion criteria for the intrahepatic Cholangiocarcinoma (CCA) service evaluation.

2. Approval

Individual transplant centres will review all suitable patients referred and determine suitability for the liver transplant pathway. These patients **do not** require approval from the National Appeals Panel or LAG Chair.

3. Registration

Transplant centres wishing to register a CCA patient should complete the Elective Liver Recipient Registration Form (**FRM4332**) with the following information and submit the form to NHS Blood and Transplant on ODT Online.

- 498 (other please specify) as primary indication with "CHOLANGICARCINOMA (CCA) PATIENT" in the free text
- Variant syndrome=Yes
- Other variant syndrome=Yes (note that all the individual variant syndrome questions should be answered on the form).
- Date of agreement to be date registered for CCA and date agreed by National NET Board

Transplant centres should subsequently email ODT Hub: Information Services (ODTRegistrationTeamManagers@nhsbt.nhs.uk) after submitting the form to inform ODT Hub: Information Services that they have registered a CRC Mets patient.

Note that these emails will be actioned by both ODT Hub: Information Services and Statistics & Clinical Research during working hours (10am - 4pm Monday - Friday).

Also, note that a report is automatically produced every day showing the patients that are active on the elective transplant list with one of the new cancer indications as the primary indication. Therefore, transplant centres should be aware that although the patient will appear on the active elective waiting list once the registration form is committed, they may not appear in the correct position on the variant syndrome until additional waiting time is added and there may be a delay if transplant centres do not email ODT Hub: Information Services.

ODT Hub: Information Services will then contact Statistical Enquiries (statistical.enquiries@nhsbt.nhs.uk) and the Lead Statistician for Liver Transplantation to confirm the patient registration.

SOP5907/5 – Registration process for liver Indications requiring additional waiting time



Blood and Transplant

Copy No:

Effective date: 18/09/2023

4. Additional Waiting Time

It has been agreed that CCA patients should receive a named patient offer within 3 months of listing. Therefore once confirmed, a Lead from Statistics & Clinical-Research will email ODT Hub: Information Services to confirm, based on recipient blood group and weight the additional waiting days that should be added.

Additional time is calculated in [Additional time for HPS and new service evaluations.sas](#) which is stored in F:\Stats & Audit\Shared\Liver\Allocation\Additional time.

Running instructions:

- Open the SAS program
- Enter the recip_id identified in the daily batchjob or email (if centre emails)
- Enter 1 for net, crc, cca, shps or vshps as appropriate (leave the four as 0)
- Run the whole program
- Open wtime3a dataset and if extra variable is greater than 0 email ODTRegistrationTeamManagers@nhsbt.nhs.uk asking for the additional waiting time specified in extra to be added for the specific recip_id e.g. "please can we add AAAA extra additional waiting days for recip_id ZZZZZ (registration_id XXXXX)."

ODT Hub: Information Services will confirm receipt of the email and add the additional waiting time. The waiting time will be automatically updated when the waiting time batch-job is next run:

- 00:05 – All organ waiting time is recalculated
- 10:00 – Liver and Intestinal waiting time is re-calculated
- 14:00 – Liver and Intestinal waiting time is re-calculated
- 18:00 – Liver and Intestinal waiting time is re-calculated

After the additional points have been added to the recipient the following should be emailed:

- Senior Statistician (Liver)
 - o To check that registration is correct, and that points have been applied correctly
- Statistical.Enquiries@nhsbt.nhs.uk
 - o To escalate if the Senior Statistician is not available
- odthuboperations.shiftmanagers@nhsbt.nhs.uk
 - o To inform Hub-Operations that a recipient has been added to the Intrahepatic Cholangiocarcinoma tier.

A representative from Statistics and Clinical Research will check and confirm the correct additional waiting time has been added.

Once confirmation has been received the recipient centre should be informed that the changes have been applied.

If the incorrect additional waiting time is added, the lead from Statistics and Clinical Research will notify ODT Hub Information Services and confirm the correct additional waiting time. The Higher/Senior Information Office will subsequently notify the [Operational Lead](#) or Operational Manager.

If the additional waiting time added is higher than requested, the Higher/Senior Information Officer will contact the database team and request urgent amendment through both service now and a phone call.

If the additional waiting time added is lower than requested, the Higher/Senior Information Officer will correct and email the Statistical lead for confirmation.

The additional waiting time will be removed, as per **SOP5844**, once the transplant centre confirms the patient has received a liver transplant.