

Effective date: 20/02/2023

Registration process for liver indications requiring additional waiting time



Effective date: 20/02/2023

Index

Summary of changes	3
Useful Information	4
Genuine hepatoblastoma patients	5
Prioritised paediatric patients	7
Acute on Chronic Liver Failure patients	9
Neuroendocrine tumour	11
Unresecteble Colorectal metastases	12
Severe or very severe hepatopulmonary syndrome	15
Intrahepatic Cholangiocarcinoma	17

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

Summary of changes

Addition of details of intrahepatic cholangiocarcinoma service evaluation.

Addition of details regarding the Information Services escalation pathway if the incorrect number of waiting days are added.

Addition of details regarding the UKELD requirement to ensure that severe or very severe HPS patients are offered through the variant syndrome pathway regardless of UKELD.

Page 3 of 18

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

Useful Information

1.	Policies and documents	. 4
2.	Definitions	. 4

1. Policies and documents

- POL195 Liver Transplantation: Selection Criteria and Recipient Registration
- POL196 Deceased Donor Liver Distribution and Allocation
- SOP5844 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.

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

Genuine hepatoblastoma patients

1.	Introduction	5
2.	Registration Process	5
<i>3</i> .	Additional Waiting Time	5

1. Introduction

Patients with genuine hepatoblastoma do not need approval from any of the other transplant centres

2. Registration Process

Transplant centres wishing to register a genuine hepatoblastoma patient 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 genuine hepatoblastoma patient.

Note that these emails will be actioned by both ODT Hub: Information Services and Statistics & Clinical Studies 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 then contact Statistical Enquiries (<u>statistical.enquiries@nhsbt.nhs.uk</u>) and the Lead Statistician for Liver Transplantation to confirm whether this is a genuine hepatoblastoma patient.

Either the Statistical Enquiries Lead or Lead Statistician for Liver Transplantation will check that the patient is not a prioritised paediatric patient or an ACLF patient and, if necessary, confirm with the transplant centre

3. Additional Waiting Time

Once confirmed, a Lead from Statistics & Clinical Studies will email ODT Hub: Information Services to inform them that it has been confirmed that the patient has hepatoblastoma and that 9000 additional waiting days should be added.

If it is confirmed that the patient doesn't have hepatoblastoma but is either a prioritised paediatric patient or has ACLF then the Lead from Statistics & Clinical Studies will email ODT Hub: Information Services to inform them of any changes required to the registration form and that 5000 and 0, respectively, additional waiting days should be added.

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. The Lead from Statistics and Clinical Studies will check and confirm the correct additional waiting time has been added.

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 Service Delivery Manager or Operational Manager.

Blood and Transplant Copy No: Effective date: 20/02/2023

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.

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

Prioritised Paediatric Patients

1.	Introduction	7
2.	Approval	7
	Registration	
4.	Additional Waiting Time	8

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 after genuine hepatoblastoma tier.

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 recip_id (if applicable).

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

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 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.

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

- 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

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 Studies 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 then contact Statistical Enquiries (<u>statistical.enquiries@nhsbt.nhs.uk</u>) and the Lead Statistician for Liver Transplantation to confirm the type of patient.

Either the Statistical Enquiries Lead or Lead Statistician for Liver Transplantation will check that the patient is a prioritised paediatric patient and, if necessary, confirm with the transplant centre.

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

4. Additional Waiting Time

Once confirmed, a Lead from Statistics & Clinical Studies will email ODT Hub: Information Services to inform them that it has been confirmed and that 5000 additional waiting days should be added.

If it is confirmed that the patient is not a prioritised paediatric patient but is either genuine hepatoblastoma or has ACLF then the Lead from Statistics & Clinical Studies will email ODT Hub: Information Services and the transplant centre to inform them of any changes required to the registration form and that 9000 and 0, respectively, additional waiting days should be added.

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. The Lead from Statistics and Clinical Studies will check and confirm the correct additional waiting time has been added.

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 Service Delivery Manager 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.

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

Acute on Chronic Liver Failure (ACLF)

1.	Introduction	.9
2.	Approval	.9
3.	Registration Process	.10
4.	Additional Waiting Time	.10

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 superurgent 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 recip_id (if applicable). It is anticipated that a decision should be made within 24 hours.

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

Blood and Transplant Copy No: Effective date: 20/02/2023

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
- "ACLF PATIENT" as tertiary indication

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 Studies 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 then contact Statistical Enquiries (<u>statistical.enquiries@nhsbt.nhs.uk</u>) and the Lead Statistician for Liver Transplantation to confirm the type of patient.

Either the Statistical Enquiries Lead or Lead Statistician for Liver Transplantation will check that the patient is an ACLF patient and, if necessary, confirm with the transplant centre.

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

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

4. Additional Waiting Time

Once confirmed, a Lead from Statistics & Clinical Studies will email ODT Hub: Information Services to inform them that it has been confirmed and that 0 additional waiting days should be added.

If it is confirmed that the patient is not an ACLF patient but is either genuine hepatoblastoma or a prioritised paediatric patient then the Lead from Statistics & Clinical Studies will email ODT Hub: Information Services and the transplant centre to inform them of any changes required to the registration form and that 9000 and 5000, respectively, additional waiting days should be added.

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.



Effective date: 20/02/2023

Neuroendocrine tumours

1.	Introduction	11
2.	Approval	11
3.	Registration	11
4.	Additional Waiting Time	.12

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 and other variant syndrome=Yes
- Date of agreement to be 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 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 Studies 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 NET or CRC 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 (<u>statistical.enquiries@nhsbt.nhs.uk</u>) and the Lead Statistician for Liver Transplantation to confirm the patient registration.

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

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 Studies will email ODT Hub: Information Services to confirm, based on recipient blood group and weight the additional waiting days that should be added.

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. The Lead from Statistics and Clinical Studies will check and confirm the correct additional waiting time has been added.

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 Service Delivery Manager 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.

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

Unresectable Colorectal Metastases

1.	Introduction	13
2.	Approval	13
3.	Registration	13
4.	Additional Waiting Time	14

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 and other variant syndrome=Yes
- · Date of agreement to be date registered

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 Studies 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 NET or CRC 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 (<u>statistical.enquiries@nhsbt.nhs.uk</u>) and the Lead Statistician for Liver Transplantation to confirm the patient registration.

Blood and Transplant Copy No: Effective date: 20/02/2023

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 Studies will email ODT Hub: Information Services to confirm, based on recipient blood group and weight the additional waiting days that should be added.

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. The Lead from Statistics and Clinical Studies will check and confirm the correct additional waiting time has been added.

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 Service Delivery Manager 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.

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

Severe or very severe Hepatopulmonary Syndrome patients

1.	Introduction	.15
2.	Approval	15
3.	Registration	.15
4.	Additional Waiting Time	.16

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 and 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 and 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.

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

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

ODT Hub: Information Services will then contact Statistical Enquiries (<u>statistical.enquiries@nhsbt.nhs.uk</u>) 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.

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 Studies will email ODT Hub: Information Services to confirm, based on recipient blood group and weight the additional waiting days that should be added.

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.

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. The Lead from Statistics and Clinical Studies will check and confirm the correct additional waiting time has been added.

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 Service Delivery Manager 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.

NHS
Blood and Transplant
Copy No:

Effective date: 20/02/2023

Intrahepatic Cholangiocarcinoma

1.	Introduction	.17
2.	Approval	.17
3.	Registration	.17
4.	Additional Waiting Time	.18

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 and other variant syndrome=Yes
- Date of agreement to be date registered

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 Studies 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 (<u>statistical.enquiries@nhsbt.nhs.uk</u>) and the Lead Statistician for Liver Transplantation to confirm the patient registration.

Blood and Transplant Copy No: Effective date: 20/02/2023

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 Studies will email ODT Hub: Information Services to confirm, based on recipient blood group and weight the additional waiting days that should be added.

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. The Lead from Statistics and Clinical Studies will check and confirm the correct additional waiting time has been added, copying in odthuboperations.shiftmanagers@nhsbt.nhs.uk for awareness.

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 Service Delivery Manager 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.