

## Registering a Patient for Transplantation

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| <i>This Management Process Description replaces<br/>NEW</i> | <b>Copy Number</b>        |
|   | Effective <b>17/03/16</b> |
| <b>Summary of Significant Changes</b>                       |                           |
| N/A   |                           |

### **Policy**

All processes included within this document should be adopted by NHS Blood and Transplant (NHSBT) and all UK based centres that register patients for solid organ or pancreatic islet transplantation

### **Purpose**

Adherence to these processes ensures patients are registered for transplantation accurately, safely and efficiently. The processes are considerate of regulatory requirements and best practice

### **Responsibilities**

#### **NHS Blood and Transplant – Transplant Support Services (TSS)**

- ODT Duty Office
- ODT Information Services
- Organ Donor Register

All policies included within this document will be adhered to by TSS. Furthermore TSS will provide expert support and guidance to help ensure registration centres comply with the policies included within this document.

This document will be routinely reviewed by NHS Blood and Transplant and, where required, updated appropriately.

#### **Registration centres**

All centres that register patients for solid organ or pancreatic islet transplantation based within United Kingdom are responsible for ensuring complete compliance to the policies included within this document.

### **Definitions**

**Active** - An active registration indicates an existing open registration.

**Suspended** - A temporary period of time during a registration period where the patient will not be considered for transplantation. Periods of suspension do not close a registration period.

**Registration Start** - The start of a registration is defined as either the date the patient is first listed with NHSBT as active or the date the patient was re-listed as active following a previously closed registration.

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**Closed Registration** - A registration is closed when the patient is reported to NHSBT as:

- removed from the list at the request of the listing centre
- transplanted
- having died while listed

**Priority status** - There are three levels of registration priority status which dictate the order in which the patient is prioritised when an appropriate donor organ becomes available:

- **Elective** patients (also referred to as routine) award the lowest priority
- **Urgent** patients are prioritised higher than elective patients
- **Super-urgent** patients are prioritised higher than urgent & elective patients

### **Applicable Documents**

[POL247](#) - Patient Registration for Transplantation

[FRM4287](#) - Liver Patients Transplanted Overseas

[FRM4324](#) - Super Urgent Liver Recipient Registration

[FRM4332](#) - Elective Liver Recipient Registration

[FRM4351](#) - Urgent Heart Recipient Registration

[FRM4352](#) - Urgent Heart Recipient Weekly Update

[FRM4659](#) - UK Cardiothoracic Transplant Audit Recipient Registration

[FRM4847](#) - Heart/Lung Recipient Registration

[FRM4291](#) - Cardiothoracic Patients Transplanted Overseas

[FRM5282](#) - ODT Online/NTN Application Form

[FRM4286](#) -Kidney Patients Transplanted Overseas

[FRM4265](#) -Supplementary Pancreas / Islet Registration Data

[FRM4120](#) - Kidney / Pancreas / Islet Recipient Registration

[FRM4155](#) - Intestinal Failure Transplant Recipient Registration

| Section | Registration Management Process Documentation |
|---------|---|
| 1       | ODT Online                                    |
| 2       | Kidney Transplantation                        |
| 3       | Pancreas Transplantation                      |
| 4       | Liver Transplantation                         |
| 5       | Cardiothoracic Transplantation                |
| 6       | Intestinal Transplantation                    |
| 7       | Multiple Organ Transplantation                |

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### 1. THE 'ODT ONLINE' APPLICATION

1.1 All elective transplant registrations should be managed by hospitals through a secure web-based application known as 'ODT Online'. The application is available 24 hours a day, 7 days a week and can be used to fully manage the elective patient registration process. ODT Online allows users to:

- Request a new elective patient registration
- Amend or close an existing elective registration
- Cross-check that the information held on the UK Transplant Registry matches the information held at the local transplant centre
- Review existing local centre elective patient registrations
- Download existing local centre patient registration information

#### 1.2 Applying for ODT Online Account Access

Access to ODT Online is available to all appropriate transplant professionals. Prior to accessing the system, new users must complete an ODT Online Account Application Form ([FRM5282](#)) which can be obtained by calling the NHSBT Service Desk. Prior to acceptance, the application must be authorised and signed by the relevant Registration Centre Transplant Director.

#### 1.3 ODT Online Training

A series of training packages are available to support and encourage the use of ODT Online. Training packages range from introductory sessions for new users to more advanced sessions for existing users that focus on some of the further benefits that ODT Online offers. To arrange ODT Online Training please contact: ODT Information Services.

#### 1.4 ODT Online Support

ODT Online support is provided between 9am and 5pm Monday to Friday (excluding public holidays) by contacting ODT Information Services:

The support line is available for transplant professionals that would like to learn more about the system and to support new and existing users should they have any questions or concerns about using ODT Online to manage the transplant registration process.

### 2. KIDNEY PATIENT REGISTRATION PROCESS

**Form:** Kidney Pancreas Islet Recipient Registration ([FRM4120](#))

**Form type:** Access via ODT Online web-application

2.1 The Kidney Pancreas Islet Recipient Registration form should be used to register all patients on the following lists:

- Elective kidney
- Elective simultaneous pancreas and kidney
- Elective pancreas alone
- Elective pancreatic islet

This form should be completed for all patients receiving a kidney transplant from both deceased and living donors. (Including patients that may choose to register for the National Living Donor Sharing Scheme.)

2.2 The form is available through the web-based application ODT Online. All relevant sections of the form must be completed in full.

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### 2.3 Selecting the correct transplant list

To ensure the patient is registered on the correct list you must state which organ is required:

- Kidney only
- Pancreas only
- Kidney and pancreas
- Pancreas Islets

The status for each organ is also required. The patient may be listed as 'active', 'suspended' or 'not required' for individual organs. Any registrations where only the kidney is set to active will result in the patient receiving offers through the National Kidney Allocation Scheme for DBD or DCD kidneys. Any registration where the pancreas or pancreatic islets are active, regardless of the kidney status, will result in the patient receiving offers through the National Pancreas Allocation Scheme.

### 2.4 Clinically urgent paediatric registrations

2.4.1 On rare occasions, paediatric patients requiring a kidney-only transplant may be entitled to be registered as clinically urgent. To qualify, the child must fall within defined clinically urgent paediatric criteria and approval must be sought from clinicians from two transplant centres independent of where the child is to be listed. Full details are included within the Kidney Allocation Policy:

[www.odt.nhs.uk/transplantation/guidance-policies/](http://www.odt.nhs.uk/transplantation/guidance-policies/)

2.4.2 Before a paediatric patient can be listed as clinically urgent, the standard registration process must be followed.

2.4.3 To list a paediatric patient as clinically urgent, the registration centre must:

- Call the Duty Office to refer a potential clinically urgent patient
- The Duty Office will provide the registration centre with the contact details of the Chair and other Members of the Paediatric Sub-Group of the Kidney Advisory Group (PSGKAG)
- The registration centre should contact the Chair and at least one other Member of the PSGKAG to request approval to list the patient as clinically urgent. The patient must meet criteria described in the Kidney Allocation Policy ([www.odt.nhs.uk/transplantation/guidance-policies/](http://www.odt.nhs.uk/transplantation/guidance-policies/)).
- If approved, the Chair of the PSGKAG (or representative) will contact the Duty Office to confirm the decision. The patient will then be listed as urgent. If approval is not granted, the PSGKAG Chair (or representative) will contact the Duty Office to confirm the decision not to approve the request and the patient will not be listed as urgent.
- In the event that there are other clinically urgent paediatric patients listed, the Duty Office will send the list of existing patients on the clinically urgent list to the PSGKAG Chair (or representative). The Chair (or representative) will then indicate the correct rank of the new clinically urgent paediatric patient and communicate this with the Duty Office to complete the registration process. The Chair will then contact the Duty Office to confirm receipt of the instruction.

### 2.5 National Living Donor Kidney Sharing Scheme Registration

Given the complex nature of the National Living Donor Kidney Sharing Scheme, the registration process for living donor and recipient pairs requires registration centres to follow specific policy which can be accessed online:

[www.odt.nhs.uk/donation/living-donation/](http://www.odt.nhs.uk/donation/living-donation/)

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- 2.6 Kidney Patients Transplanted Overseas Returning to the UK**  
**Form:** Kidney Patients Transplanted Overseas ([FRM4286](#))  
**Form type:** Paper form only (not available through ODT Online)

This form must be completed for all patients who have received a kidney transplant overseas and are subsequently returning to the UK for transplant follow-up. Completed forms should be returned to ODT Information Services. To obtain copies of this form or for advice on recording overseas transplant recipients contact ODT Information Services.

- 3. SIMULTANEOUS PANCREAS/KIDNEY, PANCREAS & PANCREATIC ISLET**  
**Form:** Kidney Pancreas Islet Recipient Registration ([FRM4120](#))  
**Form type:** Access via ODT Online web-application

- 3.1** The Kidney Pancreas Islet Recipient Registration form should be used to register all patients on the following lists:

- Elective kidney
- Elective simultaneous pancreas and kidney
- Elective pancreas alone
- Elective pancreatic islet

- 3.2** The form is available through the web-based application ODT Online. All relevant sections of the form should be completed in full.

**3.3 Selecting the correct transplant list**

To ensure the patient is registered on the correct list you must state which organ is required:

- Pancreas only
- Kidney and pancreas
- Pancreas Islets

The status for each organ is also required. The patient may be listed as active, suspended or not required for individual organs. Any registration where the pancreas or pancreatic islet is set to active, regardless of the kidney status, will result in the patient receiving offers through the National Pancreas Allocation Scheme. Registrations where only the kidney is set to active will result in the patient receiving offers through the National Kidney Allocation Scheme.

- 3.4 Supplementary Pancreas and Islet Registration Data**  
**Form:** Supplementary Pancreas and Islet Registration Data ([FRM4265](#))  
**Form type:** Paper form only (not available through ODT Online)

For all registrations involving a pancreas or pancreatic islet cells, an additional data collection form is also required: 'Supplementary Pancreas and Islet Registration Data'. The supplementary form is only available in paper form and, once complete, should be returned to ODT Information Services on the same day as the ODT Online registration is made. Forms can be returned to ODT Information Services via: E-mail or Post.

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### 4. LIVER PATIENT REGISTRATION PROCESS

#### 4.1 Super-Urgent Liver or Super-Urgent Intestinal Registration

**Form:** Super Urgent Liver Recipient Registration ([FRM4324](#))

**Form type:** Paper form only (not available through ODT Online)

4.1.1 The Super-Urgent Liver Transplant List is appropriate for both super-urgent liver patients and super-urgent intestinal patients. To register a patient on the Super Urgent Liver Transplant List the Super Urgent Liver Recipient Registration form must be completed. This form must not be used to register elective liver or elective intestinal patients as all patients registered through this form will be registered as super-urgent. ODT Online can not and must not be used to attempt to register patients as super-urgent. Additionally, using ODT Online in conjunction with the super-urgent form may result in the patient being incorrectly listed on the elective list rather than the intended super-urgent list.

4.1.2 The super-urgent liver form is available on request by contacting the Duty Office. Please ensure that all relevant sections of the form are completed in full, although please note that Section 4 of the form is only applicable when registering a patient for super-urgent intestinal transplantation.

4.1.3 When complete, the form should be sent to the Duty Office. A copy of the form should be retained by the registration centre for their records.

4.1.4 After sending the form, the registration centre must then telephone the Duty Office to confirm receipt. Prior to calling, the registration centre should ensure that they have the form available as the Duty Office will ask the caller to confirm at least three forms of patient identifiable data and, in some cases, may be requested for further information.

4.1.5 Following receipt and confirmation of this form, the Duty Office will then check whether this patient is currently on the Super-Urgent Liver Transplant or Elective Liver List. If not, the Duty Office will process the new registration. If the patient is currently on the list, the Duty Office may contact the centre to confirm the correct patient listing requirement.

4.1.6 The Duty Office send an anonymised version of all new super-urgent liver or super-urgent intestinal registrations to each of the other UK based liver transplant centres. This offers an opportunity for peer review, validation and challenge against the super-urgent liver selection criteria.

#### 4.1.7 Periods of suspension on the Super-Urgent Liver Transplant List

A patient suspended from the Super-Urgent Liver Transplant list can be reactivated within 5 days and maintain their position on the list. Once the patient is suspended for over the 5 days, the patient will then be removed from the Super-Urgent Liver Transplant list and will not automatically be moved to the elective list. If the patient is removed from the super-urgent list and needs to be registered on the elective list then an elective registration form must be completed. Note, the five day maximum suspension period rule does not apply to Super-Urgent Intestinal Patient Registrations, for whom no such restriction is applied.

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#### 4.2 Elective Liver Registration

**Form:** Elective Liver Recipient Registration ([FRM4332](#))

**Form type:** Access via ODT Online web-application

4.2.1 To register a patient on to the Elective Liver Transplant List an Elective Liver Recipient Registration Form must be completed. This form should be completed for patients receiving an elective liver from both deceased and living donors (including liver-only intestinal failure patients).

4.2.2 This form must **not** be used if the patient is intended to be registered as super-urgent.

4.2.3 The form is available through the web-based application ODT Online  
All sections of the form should be completed, failure to do so may result in the patient not being registered onto the national liver transplant list until such time that all missing or invalid information is reported or corrected.

4.2.4 On rare occasions a patient may be listed as super-urgent but is no longer considered to require super-urgent status. To transfer the patient from the super-urgent list to the elective list, the patient must first be removed from the super-urgent list. To do this, the registration centre should contact the Duty Office. Once removed, the patient should then be listed on the elective liver transplant list as described in Sections 4.2.1 to 4.2.3.

#### 4.3 Liver Patients Transplanted Overseas Returning to the UK

**Form:** Liver Patients Transplanted Overseas ([FRM4287](#))

**Form type:** Paper form only (not available through ODT Online)

4.3.1 This one-page paper form must be completed for all patients who have received a liver transplant overseas and are subsequently returning to the UK for long-term follow-up. Completed forms should be returned to ODT Information Services. To obtain copies of this form or for advice on recording overseas transplant recipients contact ODT Information Services.

#### 4.3.2 Liver Sequential Data Collection

For all patients actively listed for a liver transplant, there is a requirement to routinely complete a Liver Sequential Data Collection Form. This form should be completed and submitted every time the patient is seen in clinic. Failure to do so may result in disadvantaging the patient through incorrect prioritisation in the new liver offering scheme that the Liver Advisory Group is developing. PDF copies of this form can be obtained by contacting ODT Information Services.

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### 5. INTESTINAL FAILURE TRANSPLANT PATIENT REGISTRATION PROCESS

#### 5.1 Elective Intestinal Failure Transplant Registration

**Form:** Intestinal Failure Transplant Recipient Registration ([FRM4155](#))

**Form type:** Access via ODT Online web-based application

5.1.1 To register a patient on to the elective intestinal transplant list an Intestinal Failure Transplant Recipient Registration form must be completed. This form should be completed for patients with intestinal failure who require any of the following organ transplants:

- bowel only
- bowel & pancreas
- liver, bowel & pancreas
- multivisceral
- modified multivisceral transplant

5.1.2 This form must **not** be used if the patient is intended to be registered on the Super-Urgent Liver Transplant List or the elective liver transplant list. Those patients who require a super-urgent intestinal transplant should be registered using the Super Urgent Liver Recipient Registration form (Section 4.1). Those patients who require a liver-only transplant due to intestinal failure should be registered using the elective liver registration form (Section 4.2).

5.1.3 The Intestinal Failure Transplant Recipient Registration form is available through the web-based application ODT Online. Please complete all sections as failure to do so may cause the patient not to be listed until missing or incorrect information is available or corrected. This includes providing the details on the specific organs/tissues that the patient requires as well as the patients HLA type. Appropriate offering is reliant on this information.

5.1.4 If the specific organs/tissues that the patient requires changes, or certain aspects of the patient's clinical status change, an Intestinal Failure Sequential Data Collection Form should be completed via ODT Online. Failure to do so may result in disadvantaging the patient through incorrect prioritisation in the offering process.

#### 5.2 Super-Urgent Intestinal Registration

**Form:** Super Urgent Liver Recipient Registration ([FRM4324](#))

**Form type:** Paper form only (not available through ODT Online)

5.2.1 Refer to Sections 4.1.1 to 4.1.7 for details on how to register a super-urgent intestinal patient.



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### 6. CARDIOTHORACIC TRANSPLANT PATIENT REGISTRATION PROCESS

#### 6.1 Urgent Heart Registration

**Form:** Urgent Heart Recipient Registration ([FRM4351](#))

**Form type:** Paper form only (not available through ODT Online)

6.1.1 To register a patient on to the Urgent Heart Transplant List the Urgent Heart Recipient Registration form must be completed. This form must not be used to register elective heart patients as all patients registered through this form will be registered as urgent. ODT Online can not and must not be used to attempt to register patients as urgent. Using ODT Online in conjunction with the urgent paper form may result in the patient being incorrectly listed on the elective list rather than the urgent list.

6.1.2 The urgent heart registration form is available on request from the Duty Office:

6.1.3 Please ensure that all relevant sections of the form are completed in full. When complete, send all pages to the Duty Office. The original form should be retained by the registration centre for their records.

6.1.4 After sending the form, the registration centre must then telephone the Duty Office to confirm receipt. Prior to calling, the registration centre should ensure that they have the form available as the Duty Office will ask the caller to confirm at least three forms of patient identifiable data and, in some cases, may be requested for further information.

6.1.5 Following receipt and confirmation of this form, the Duty Office will then check whether this patient is currently listed. If not, the Duty Office will input the registration into the UK Transplant Registry. If the patient is currently registered, the Duty Office may contact the centre to confirm the correct patient listing requirement.

#### 6.1.6 Periods of suspension from the Urgent Heart List

An urgent heart registration may be suspended for up to a period of 14 days and continue to retain their original urgent registration date. Any periods of suspension that exceed 14 days will be removed from the list and a new urgent heart registration form will be required should the patient require re-listing on a future date. Requests to suspend or re-activate an urgent heart patient should be made by contacting the Duty Office:

#### 6.1.7 Weekly Urgent Heart Listing Update

**Form:** Urgent Heart Recipient Weekly Update ([FRM4352](#))

**Form type:** Paper form only (not available through ODT Online)

This form should be completed for any patient who has been on the urgent heart list for more than 7 days. This form should be completed every 7 days with up to date information throughout the entire duration of the urgent heart registration. The form should be sent to the Duty Office:

6.1.8 If a patient is reactivated following a period of suspension from the urgent list, a new Weekly Update form should be submitted at that time. Do not use this form for new registrations on the urgent list. All new urgent registrations should be made using the Urgent Heart Recipient Registration Form using the process described in Section 6.1.1 to 6.1.5.

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### 6.2 Elective Heart, Lung or Heart/Lung Block Registrations

**Form:** Heart/Lung Recipient Registration ([FRM4847](#))

**Form type:** Access via ODT Online web-based application

6.2.1 The Heart/Lung Recipient Registration form should be used to register all patients on to the following lists only:

- Elective heart
- Elective lung
- Elective heart / lung

Additionally this form should also be completed for patients receiving an elective lung from a living donor.

6.2.2 This form must **not** be used if the patient is intended to be registered for an urgent heart

6.2.3 The form is available through the web-based application ODT Online  
All relevant sections of the form should be completed in full.

#### 6.2.4 **Selecting the correct transplant list**

To ensure the patient is registered on the correct list you must state which organ is required and indicate for each organ whether the patient is to be listed as active or suspended

- Heart only
- Lung only
- Heart and Lung

#### 6.2.5 **Directed Living Lung Donor Registration**

Patients receiving a lung transplant from a living donor must be registered through ODT Online in the usual way (6.2.1 to 6.2.5).

#### 6.2.6 **Cardiothoracic Patients Transplanted Overseas Returning to the UK**

**Form:** Cardiothoracic Patients Transplanted Overseas ([FRM4291](#))

**Form type:** Paper form only (not available through ODT Online)

This form must be completed for all patients who have received a heart transplant overseas and are subsequently returning to the UK for long-term follow-up. Completed forms should be returned to ODT Information Services. To obtain copies of this form or for advice on recording overseas transplant recipients contact ODT Information Services.

#### 6.2.7 **Cardiothoracic Transplant Audit Recipient Registration Form**

**Form:** UK Cardiothoracic Transplant Audit Recipient Registration ([FRM4659](#))

**Form type:** Access via ODT Online web-based application

To complete the heart, lung or heart/lung block registration process this two page form must be completed for all patients that are listed for a heart or lung only or heart/lung block transplant. The form is available through the web-based application ODT Online. All relevant sections of the form should be completed in full.

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### 7. MULTIPLE ORGAN TRANSPLANT LIST MANAGEMENT

7.1 Registrations for the following simultaneous transplants are sufficiently common that they have been included in relevant earlier sections of this document:

Simultaneous kidney and pancreas (Section 3)  
Intestinal failure patients (Section 5)  
Heart & Lung Block (Section 6)

7.2 On occasions patients are listed for a range of combined solid organ transplants such as a simultaneous kidney & heart or simultaneous kidney and liver transplantation. This section provides guidance on how to register patients for combined transplant therapies.

7.3 An elective registration form must be submitted for each organ type to be included in the multiple organ patient registration. For example to register a patient that requires a combined liver and kidney transplant a Kidney, Pancreas, Islet Recipient Registration form (Section 2) and an elective Liver Transplant Recipient Registration Form (Section 4) must be completed and submitted via ODT Online.

7.4 With the exception of simultaneous pancreas and kidney transplants, it is not necessary to provide the patient HLA type, antibody profile or sensitisation (reaction frequency) information (Section 4 of [POL247](#)) as part of the kidney registration for a multiple organ transplant. Multiple organ transplants are not offered kidneys via the National Kidney or Pancreas Allocation Scheme.

#### 7.5 **Selecting the correct multiple organ transplant list**

Multiple-organ registrations are complex in nature and as such centres are requested to contact ODT Information Services on each occasion they wish to make a multiple organ transplant (excluding those identified in Section 7.1). Information Services will provide registration support to ensure the patient is correctly listed.

#### 7.6 **Amending a Multiple Organ Patient Registration**

A centre is again required to contact Information Services to seek support on making any type of multiple organ registration amendment. This could include re-activation to or suspensions from the list, removal from the list or to report a patient death. It is important to note that if a patient is to be removed from the waiting list that the status of both organ types is updated to reflect this via ODT Online (Section 1).

#### 7.7 **Registration Support for Multiple Organ Transplant Listing**

For advice and guidance on handling multiple organ registrations, ODT Information Services can be contacted during standard office hours; Monday to Friday 9am to 5pm (excluding public holidays).