POLICY POL247/1

Patient Registration for Transplantation

This Policy replaces *NEW*	**Copy Number**
	Effective **17/03/16**

Summary of Significant Changes

N/A

Policy

This policy has been created by Transplant Support Services (TSS) on behalf of NHS Blood and Transplant (NHSBT).

The policy has been considered and approved by the Transplant Policy Review Committee (TPRC), who act on behalf of the NHSBT Board and are responsible for annual review of the document herein.

Last updated: June 2015

Approved by TPRC: September 2015

The aim of this document is to provide a policy to ensure patients are registered for transplantation accurately, safely and efficiently. The policies are considerate of regulatory requirements and best practice.

These criteria include transplant listing policy for patients being listed for transplantation from a living and deceased donor. This document references MPD1211 – Registering a Patient for Transplantation

All policies within this document should be adopted by NHS Blood and Transplant and all UK based centres that are involved in the registration of patients for solid organ or pancreatic islet transplantation.

1 PRE-REGISTRATION

1.1 Patient selection

All patients must meet organ specific selection criteria as defined in the organ specific Selection Policies available on the ODT Clinical website:
www.odt.nhs.uk/transplantation/guidance-policies/

1.2 Eligibility for solid organ transplantation under the NHS

The Human Tissue Act 2004 and Human Tissues (Scotland) Act 2006 require centres to record the NHS Group eligibility of every patient listed for transplantation in the UK. It is the responsibility of the registering unit to determine eligibility. Guidance may be obtained from the relevant national Department of Health.

2 PATIENT CONSENT FOR THE USE OF INFORMATION

2.1 The NHS Code of Practice on Confidentiality requires that consent is gained from all patients prior to being registered for any transplant:
www.gov.uk/government/publications/confidentiality-nhs-code-of-practice

2.2 The NHSBT Patient Consent for Information Scheme ensures all patients are able to provide informed consent for NHSBT to collect and store information on the UK Transplant Registry.

2.3 Registration centres must therefore ensure that all patients are provided with the NHSBT. booklet 'Giving Consent for the Use of Your Information' and that they are able to provide fully informed consent. This should be documented in the clinical records and recorded on the UK Transplant Registry as part of the registration process. Copies of the information booklet can be ordered by contacting Information Services.

2.4 Levels of consent

A patient may agree to one of three levels of consent:

- **Full consent:** Full information from registration, transplantation and post-transplant follow-up will be recorded.

- **Partial consent:** Usually this will limit the information recorded to that needed for the purposes of registration, offering and allocation. Information purely for the purposes of audit or analysis will not be recorded.

- **No consent*:*** Patients must be made aware that it will not be possible to record any information on the UK Transplant Registry and so the patient will not be included in organ allocation or be considered for transplantation. This must be documented in the patient's clinical records.

A patient may change their level of consent at any time.

2.5 Auditing Patient Consent Compliance

Centres that register patients are audited on a quarterly basis by NHSBT to ensure that patient consent has been recorded for all registrations.

2.6 Requests for Personal Information

Patients are entitled to request to view all personal information recorded on the UK Transplant Registry and can do so by contacting NHSBT customer services: customer.services@nhsbt.nhs.uk.

3 NEW PATIENT REGISTRATIONS

3.1 All patients who are to be listed for deceased or living donor transplantation should be registered with NHSBT prior to transplantation.

3.2 The registration process can differ according to the type of transplant required and patient priority status:

- **Elective patient registrations** should be processed using the secure web-based software application known as 'ODT Online' Patient Registration for Transplantation (MPD1211).
- **Urgent & super-urgent patient registrations** should be processed by completion of paper-based returns Registering a Patient for Transplantation (MPD1211)
- **National Living Donor Kidney Sharing Scheme registrations** should be processed following agreed policy available on the ODT Clinical Website: www.odt.nhs.uk/donation/living-donation/

4 AMMENDING EXISTING PATIENT REGISTRATIONS

4.1 Registrations should be amended to include additional information or to record changes in the patient's clinical status. All registration amendments should be made by the registration centre through the ODT Online application.

4.1.1 **Temporary suspension of patients from the list**
The centre may decide that the patient is unfit or unavailable for transplantation for a period of time or that they would like to transfer the patient to another centre. It is the responsibility of the transplant centre to notify NHSBT of the start and end of the suspension period.

4.1.2 **Removing a patient from the list**
The centre may assess the patient to be no longer suitable for or no longer require transplantation. A removal will close the patient registration. A patient whose registration is closed by removal will need to be re-registered on the appropriate transplant list should they be re-assessed to require transplantation.

4.1.3 **Receiving a transplant while listed**
When a patient receives a transplant the centre should notify the Duty Office within 24 hours that the transplant has taken place and provide the details of the recipient who received the graft. The Duty Office will then record the transplant and the recipient will be removed from the transplant list.

4.1.4 **Death notification**
If a patient dies while listed for transplantation the death should be reported to NHSBT at the earliest opportunity.

4.1.5 **Change of patient details**
All known changes in patient demographic or clinical details should be reported to NHSBT at the earliest opportunity.

4.1.6 **Transferring a listed patient to an alternative centre**
When a listed patient is transferred to another centre, the new centre should register the patient as a new registration. ODT Information Services will be aware that this patient is currently actively listed or suspended and will contact the existing registration centre to seek their agreement for the transfer.

To ensure the patient registration remains continuous and that the waiting time is carried over to the new registration centre, transferring patients should not be 'removed' from the original centre list as this will result in the loss of waiting time accrued. On completion of the transfer, ODT Information Services will write to the new registration centre to confirm the data held for the patient and to the previous centre to confirm the transfer has been completed. The new registration centre should carefully check that the new registration details are accurate and not unduly affected by the transfer.

5 RECIPIENT HLA TYPE AND ANTIBODY SCREENING

5.1 This information is required for all of the following types of patient registration:

- Kidney
- Simultaneous kidney/pancreas or pancreas alone
- Pancreatic islet
- Intestinal transplantation

5.2 Recipient HLA Type

The HLA type (tissue type) of the patient must be reported in compliance with the 'Minimum Resolution for Donor and Patient HLA Types Requirements:

www.odt.nhs.uk/pdf/minimum_typing_requirements_for_reporting_HLA_types_2009.pdf

5.3 Antibody Defined and 'Other' Unacceptable HLA Antigen Reporting

The HLA antigen specificities deemed unacceptable for the patient must be given to ensure that HLA incompatible donors are not offered. Guidance for the definition of unacceptable antigens can be found at

http://www.bshi.org.uk/BSHI_BTS_Ab_Guidelines_Revision_June_2014.pdf

An antibody may be recorded for a patient if a defined HLA antibody is present or if it is otherwise deemed necessary to avoid exposing the patient to particular antigens (referred to as 'other unacceptable antigens'). Antibody-defined and 'other' unacceptable antigens are reported in separate sections of the registration form but are treated the same in excluding certain donors.

5.4 Sensitisation & residual reaction frequency

Clinically relevant 'overall' and 'residual' reaction frequencies should be provided.

5.5 Antibody Profile and Sensitisation Update Requirements

Centres are required to report any known changes in antibody profile or residual reaction frequency. The recommended review periods for all listed patients can be found at:

http://www.bshi.org.uk/BSHI_BTS_Ab_Guidelines_Revision_June_2014.pdf

5.5.1 If no updates are required, no action needs to be taken.

5.5.2 If updates to the antibody profile or sensitisation values are required, the registration centre should make the amendment to the existing patient registration through ODT Online, (MPD1211).

6 TRANSPLANT LIST AUDITING

6.1 On rare occasions, the status of patients listed for transplantation does not accord with that at the local centre. Transplant list discrepancies can lead to patients potentially missing out on an offer of an organ. To reduce the risk of patient disadvantage, registration centres are required to regularly review their local transplant list against the list held by NHSBT.

6.2 Frequency of centre transplant list auditing

NHSBT recommend that centres review the accuracy of their centre-specific transplant lists regularly:

6.2.1 For elective transplant lists, the recommended minimum review frequency is once a week using the configurable waiting list option available in ODT Online.

6.2.2 For urgent heart and super-urgent liver transplant lists the recommended review frequency is every day using the lists provided daily by the Duty Office.

6.3 Discrepancy notifications

All discrepancies should be resolved as expediently as possible.

6.3.1 **For urgent or super-urgent registration discrepancies** the centre should immediately contact the Duty Office, available 24 hours a day.

6.3.2 **For elective registration discrepancies** the centre should contact ODT Information Services, available 9:00 to 17:00, Monday to Friday (excluding public holidays).

6.4 Following notification of a discrepancy:

6.4.1 NHSBT will amend the registration appropriately.

6.4.2 Where the discrepancy may have disadvantaged the patient, NHSBT will undertake Patient Disadvantage Investigation (PDI) to ascertain whether the patient may have missed out on the offer of an organ.

6.4.3 The findings will be shared with the relevant centre and/or H&I Laboratory.

6.4.4 If the patient may have missed one or more offers of an organ due to the discrepancy, ODT Information Services will agree corrective action with both the relevant registration centre and Chair of the relevant Advisory Group.

6.4.5 Remedial action varies across the organ specific transplant lists and is detailed in the organ specific allocation policies:
http://www.odt.nhs.uk/transplantation/guidance-policies/

6.4.6 Discrepancies will be reported as a Clinical Governance Incident by ODT Information Services or the Duty Office, as appropriate.

6.4.7 Where a patient is disadvantaged by an error, the NHSBT Duty of Candour may apply: Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 20.

6.5 Accuracy of patient registration details

Centres should ensure they have robust patient registration processes in place to ensure the registration information provided to NHSBT is accurate. Inaccuracies may lead to patient harm including inappropriate transplantation or impaired access to transplant, other serious untoward incidents, inaccurate audit reporting or misinformation for research, service development and performance reporting.