

NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE
BOWEL ADVISORY GROUP

**ALLOCATION SCHEME – REPORTING OF ELECTIVE REGISTRATION
DATA**

INTRODUCTION

1. The new process and forms for registering elective patients on the intestinal transplant list commenced in July 2013 as part of the project to automate allocation of organs and incorporate data on intestinal registrations, transplants and follow-up onto the UK Transplant Registry.
2. Following the implementation of these new processes and forms, issues have been identified with the collection of some data items. This paper details these issues and requests support from all centres in the provision of data.

ISSUES IDENTIFIED

HLA data

3. It was agreed that HLA data would be provided for all patients being registered for an elective Intestinal Failure transplant and the new forms and validation rules were developed in this way. However, some centres have stated that this information is not available for their patients. Therefore, this conflicts with the design of the new scheme.
4. If unacceptable HLA specificities are not provided, patients will miss out on points in the allocation scheme and may receive inappropriate offers. Additionally, although tissue typing is not currently used for matching, if analysis of transplant outcome by match grade is requested in the future to inform changes to the allocation scheme, it is necessary to have these data reported for all patients.

INR

5. It was agreed that INR would be provided and validation rules have been set up to ensure it is completed, to enable the calculation of the UKELD score for patients. This would allow analyses to be performed to determine if UKELD was a more appropriate allocation measure. However, one centre has said this measurement is not collected for their patients.

ACTION

6. Members are reminded to ensure their centre collects and reports all the data items that have been agreed by the BAG as part of the new data collection and allocation procedures. **Patients will not be registered until all mandatory items, shown in Appendix I, are reported.** It is essential that all data items are accurately reported but non-mandatory items will not delay the registration.

Appendix I**Mandatory data items on the Intestinal Transplant Registration Form**

Recipient Details
Transplant Centre
Recipient Surname
Recipient Forename
NHS Group status
Date of Birth
Blood Group
Ethnic Origin
Country of Residence
Postcode
Registration Details
Registration status (Active/Suspended)
Organs Required
Paediatric donor organ required
Previous transplants
Primary Indication for transplant
Recipient weight
Recipient height
HLA data (and any unacceptable specificities)
Investigation results pre-transplant
Serum Creatinine
INR
Serum Bilirubin
Serum Sodium
Clinical Status
Patient location (outpatient/ward/ICU/HDU)
Restricted venous access