

**NHS BLOOD AND TRANSPLANT
ORGAN & TISSUE DONATION AND TRANSPLANTATION DIRECTORATE
KIDNEY ADVISORY GROUP**

MINIMUM KIDNEY DATASET

INTRODUCTION

- 1 All transplant units return data to NHSBT when registering a patient on the kidney transplant waiting list, then once the patient has reached 3 months post-transplant and then on each anniversary of the transplant. These data are returned to NHSBT via the following forms, Kidney/Pancreas/Islet recipient registration form (FRM4120), Kidney 3 month follow up (FRM4188) and Kidney annual follow up (FRM4189).
- 2 As part of the National Renal Programme (NRP) data collection, it was observed that key variables, such as delayed graft function, had a high percentage of missing data. This raises concerns about the integrity of the dataset and the ability to accurately assess the effectiveness of graft function. Addressing this issue is essential to ensure robust analyses and reliable outcome assessments.
- 3 This paper shows the data collected by NHSBT for kidney transplantation and level of missing data in the kidney dataset. Specifically, this concerns missing data where a follow-up form has been returned but not all of the fields have been completed. The aim of this paper is to aid KAG members to review the minimum dataset, i.e. the required data fields, and decide whether any amendments are required.

DATA AND METHODS

- 4 This paper summarises the data fields collected by NHSBT through the registration form and the follow up forms, with details on which fields are currently required, which are available to be collected through NTN and ODT Online. Most centres use ODT Online, with 8 centres using NTN (Bristol, Cardiff, Edinburgh, Glasgow, Leeds, Portsmouth, Royal Free, Sheffield).
- 5 Data were obtained from the UK Transplant Registry on all data collected through these forms between 01 January 2019 and 30 June 2024 for registration and form 1 January 2019 to 31 December 2023 for follow-up, to summarise the amount of missing data. This highlights missing data where a follow-up form has been returned and does not take into account data missing because of non-return or loss to follow-up.

REGISTRATION FORM

- 6 Table 1 shows the registration form variables with high levels of missing data. The full list of variables along with data completeness is shown in Appendix table 1. The tables also indicates whether they are currently mandatory fields and whether they can be provided by centres using NTN.
- 7 While some of the variables identified with high proportions of missing data are not collected at NTN sites, the missing values come from all centres.

Table 1 Details on data collected through registration form, for variables with significant missing data or unavailable through NTN

Field	NTN File	Required?	Missing data n (%)
CMV Status	Yes		1943 (10)
HCV Status	Yes		4277 (21)
HBV Status	No		4266 (21)
HIV Status	No		4273 (21)
Weight	No		2726 (14)
Height	No		2191 (11)
Primary disease code	Yes	Required	0 [2984 -15% unknown]
Ethnic group	Yes	Required	0 [708 -4% unknown]

FOLLOW UP FORMS

- 8 Table 2 shows the variables collected on the follow up forms with high proportions of missing data. The full list of variables collected and level of missing data are shown in Appendix table 2. The table also indicates whether these are currently mandatory fields and whether the data can be submitted by centres using NTN.
- 9 As with the registration data, the missing data are spread across all centres and not limited to NTN sites.

Table 2 Details on data collected through follow up form(s), for variables with significant missing data or unavailable through NTN

Field	NTN File	Required	Missing 3-months n (%)	Missing 1-year n (%)
Number of treated rejection episodes	No		6162 (39)	6067 (44)
Recurrent disease	No		3640 (23) (further 21% unknown)	3664 (27)
Recipient weight	No		6198 (40)	6479 (47)
Recipient height	No		13915 (89)	12312 (90)
Graft function onset	No		2431 (16)	2001 (15)
Developed malignancy	No		4792 (31)	4658 (34)

SUMMARY

- 10 Within the forms returned to NHSBT, there are a number of variables, which are key in analysing the outcomes for recipients post-listing and post-transplant, with high proportions of missing data due to incomplete follow-up. These include early onset graft function and number of rejection episodes.
- 11 Of those fields identified in this paper, most are not currently required fields. Some of these variables are also not collected from centres using NTN.

RECOMMENDATIONS

- 12 KAG members are asked to consider whether any of the variables identified with high proportions of missing data should be made mandatory in order to increase the level of data completeness.
- 13 If accepted, the recommendation would need to be considered operationally by both the centres and the ODT Information Services teams. They would need to explore viable options for implementation, such as introducing manual processes to ensure data collection is complete, or transitioning centres to the ODT Online system to capture all required fields, including primary renal disease and onset of graft function.
- 14 Additionally, KAG members are asked to consider whether there should be a broader requirement for centres using the NTN system to ensure their datasets are fully complete.

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Appendix Table 1 show the full list of variables collected through the registration form. This shows the number of missing data points for each field between 1 January 2019 and 30 June 2024.

Field	NTN File	Required?	Missing data n (%)
Recipient details section			
Transplant Centre Name	Yes	Required	-
Surname	Yes	Required	-
Forename	Yes	Required	-
Hospital Number	Yes		-
Address	Yes	Required	-
Postcode	Yes	Required	-
Telephone 1	Yes		-
Telephone 2	Yes	Optional	-
Date of birth	Yes	Required	-
Sex	Yes	Required	48 (0.2)
CMV Status	Yes		1943 (10)
HCV Status	Yes		4277 (21)
HBV Status	No		4266 (21)
HIV Status	No		4273 (21)
Group Status	Yes	Required	-
Nationality	No	Required	-
Country of residence	No	Required	-
NHS Number	No		200 (1.0)
Special Instructions	Yes		-
Consider en-bloc	No		-
Registration details section			
Kidney (Active / Suspended)	Yes	Required	-
Pancreas (Active / Suspended)	Yes	Required	-
Islets (Active / Suspended)	No	Required	-
Organ Required	Yes	Required	-
Weight	No		2726 (14)
Height	No		2191 (11)
Dialysis status	No	Required	-
Dialysis start date	No		-
Dialysis centre code	No		-
Treated at Paediatric unit	No		-
Primary disease code	Yes	Required	0 [2984 -15% unknown]
Primary disease (other)	Yes		-
Number of previous kidney grafts	Yes		-
Number of previous pancreas grafts	Yes		-
Number of previous simultaneous kidney and pancreas grafts	Yes		-
Number of previous pancreas islets grafts	No		-
ABO	Yes	Required	-
Rhesus	Yes	Required	-

Ethnic group	Yes	Required	0 (708 -4% unknown)
Ethnic group other	No		-
Mean daily insulin requirement (units)	No		
Recipient HLA Data			
HLA	Yes	Required	
Sensitisation Status			
HLA AB Screening	No		
Screening methods: CDC	No		
Screening methods: FC	No		
Screening methods: ELISA	No		
Date of evaluation of sensitisation	No		
Relevant reaction frequency vs T/PBL %	Yes		
Antibody class	Yes		
Relevant reaction frequency vs B/CLL %	Yes		
Antibody class	Yes		
Do the HLA in Section 5 account for all?	No		
T/PBL(%)	No		
B/CLL(%)	No		
Sensitisation Data Assessed by:	No		
Other HLA Data			
Has the unacceptable HLA Phenotype been determined	No		
Antibody defined unacceptable HLA specificities	Yes		
Other unacceptable HLA specificities	No		
Match grade	Yes		

Appendix Table 2 show the full list of variables collected through the follow up forms. This shows the number of missing data points for each field between 1 January 2019 and 31 December 2023.

Field	NTN File	Required	Missing 3-months n (%)	Missing 1-year n (%)
Recipient and transplant details				
Transplant Centre	Yes	Required	-	-
Surname	Yes	Required	-	-
Forename	Yes	Required	-	-
NHS Number	No		200 (1.0)	200 (1.0)
Hospital Number	Yes		-	-
Date of Birth	Yes	Required	-	-
Transplant Date	Yes	Required	-	-
Graft No	Yes		-	-
Organ Transplanted	Yes		-	-
Follow up details				
Transferred for follow up	Yes			

Lost to follow up	No			
Lost to follow up reason	No			
Number of treated rejection episodes	No		6162 (39)	6067 (44)
Date of first rejection	No		-	
Recurrent disease	No		3640 (23) [further 20.9% unknown]	3664 (27)
Failure of transplant	Yes		15 (0.1)	8 (0.1)
Date of failure	Yes		-	1 (0.0)
Cause of failure	Yes		0 [471 unknown – 3.0]	0 [142 unknown 1.0]
Other cause of failure	Yes			
Date of return to dialysis	Yes		316 (44)	205 (62)
Date of graft nephrectomy	Yes		760 (77)	591 (93)
Patient death	Yes		46 (0.3)	55 (0.4)
Date of death	Yes		-	-
Cause of death	Yes		0 [100 – 33% unknown]	0 [99 unknown 46%]
Secondary cause of death	No		-	
Other cause of death	Yes			
Clinical assessment of graft function				
Date of last assessment	Yes			
Recipient weight	No		6198 (40)	6479 (47)
Recipient height	No		13915 (89)	12312 (90)
Serum creatinine	Yes	Required	1437 (9)	1015 (7)
Date of serum creatinine test	Yes		1437 (9)	1015 (7)
Graft function onset	No		2431 (16)	2001 (15)
Has the graft started to function	No		1 [16 unknown – 0.6%]	0 [32 unknown – 1%]
Date of end of dialysis	Yes		10 (0.4)	
Current immunosuppressive drugs				
Date of current immunosuppressive drugs	Yes			
Ciclosporin	Yes		1487 (10) [further 4222 – 27% not reported]	1113 (8.1) [further 3776 – 27% not reported]
Azathioprine	Yes		1487 (10) [further 4161 – 27% not reported]	1113 (8.1) [further 3645 – 26% not reported]
Tacrolimus	No		1487 (10) [further 2373 -15% not reported]	1113 (8.1) [further 2418 – 17% not reported]
Mycophenolate	No		1487 (10) [further 2897	1113 (8.1) [further

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			-19% not reported]	2896 – 21% not reported]
Prednisolone	No		1487 (9.5) [further 1895 -12% not reported]	1113 (8.1) [further 1695 – 12% not reported]
Other	Yes		1487 (9.5) [further 3618 -23.1% not reported]	1113 (8.1) [further 2750 – 20% not reported]
Other - details	Yes			
Malignancy				
Developed malignancy	No		4792 (31)	4658 (34)
Date of diagnosis	No			
Details of malignancy	No			