

NHS BLOOD AND TRANSPLANT

LIVER ADVISORY GROUP

COMPLIANCE WITH SEQUENTIAL DATA COLLECTION SUBMISSION

BACKGROUND

- 1 Transplant centres are required to provide NHS Blood & Transplant (NHSBT) with accurate and regular information regarding patients who are active on the UK elective liver transplant list. This is to enable the matching run produced by ODT Hub Operations to accurately calculate patients' transplant benefit scores (TBS) reflecting the most recent sequential update and rank them in the new National Liver Offering Scheme (NLOS) appropriately.
- 2 A revised version of the Sequential Data Collection (SDC) form was implemented on 14th December 2017 covering all the components of the TBS score as well as questions relating to whether recipients would like to consider offers from particular donors. All centres were asked to provide updates on at least a three monthly basis while patients were active on the UK elective liver transplant list.
- 3 NHSBT have established reports which are sent to transplant centres on a regular basis detailing all the patients active on the transplant list and whether the patient requires a sequential update.
- 4 Prior to March 2018, NHSBT required sequential updates for all elective liver transplant patients regardless of whether the patient had a variant syndrome or not. However, at the LAG core group in March 2018, it was agreed that transplant centres should only send sequential updates for chronic liver disease (CLD) or hepatocellular carcinoma (HCC) patients and **not** for variant syndrome patients. This was to prevent variant syndrome patients whose UKELD oscillated around 49 transitioning to the chronic liver disease pool inappropriately.
- 5 This paper reports on the elective liver SDC form return rates as at 27 April 2025.

METHODS

- 6 Data on all elective SDC forms received by ODT Hub Information Services between 14 December 2017 and 27 April 2025 were extracted from the UK Transplant Registry (UKTR) on 28 April 2025. Data on all patients active on the elective CLD and HCC list and for whom the TBS score was applicable on the 27 April 2025 were also extracted.

RESULTS

- 7 **Table 1** shows the number of sequential data collection forms ODT Hub Information Services have received between 14 December 2017 and 27 April 2025. The number of forms per transplant centre ranged from 470 to 5695 with a median of 2112 SDC forms per transplant centre. Four of the seven transplant centres have submitted a median of two SDC forms per patient.

Table 1 Number of sequential data collection forms received by ODT Hub Information Services, 14 December 2017 to 27 April 2025, by transplant centre			
Transplant centre	No. of SDC forms	No. of patients with returned SDC forms	Median (IQR; range) number of SDC forms per patient
Newcastle	470	156	2 (1, 3; 1, 17)
Leeds	2294	624	2 (1, 5; 1, 27)
Cambridge	1784	540	2 (1, 4; 1, 21)
Royal Free	1869	561	2 (1, 4; 1, 21)
King's College	5695	1142	3 (1, 6; 1, 72)
Birmingham	5613	1144	3 (1, 6; 1, 35)
Edinburgh	2112	416	4 (1, 7; 1, 40)
Total	19837	4583	3 (1, 6; 1, 72)

- 8 Four hundred and sixty four patients were active on the elective CLD/HCC transplant list and for whom the TBS score would be applicable on 27 April 2025. Combined cardiothoracic and liver patients, paediatric, hepatoblastoma and variant syndrome patients were excluded along with patients not active on the transplant list.
- 9 **Table 2** shows that NHSBT have received either an SDC form or a registration form within the last 30 days for 143 of 464 patients active on the elective CLD/HCC transplant list. **Table 2** also shows that NHSBT have not received any SDC forms for 62 (13%) patients who had been active on the transplant list for more than 30 days.

Table 2 Time since last SDC/registration update for active elective CLD/HCC adults, small adults and large paediatrics, as at 27 April 2025, by transplant centre						
Transplant centre	Time since last SDC/ registration update				Total	No. of patients active for at least 31 days and a SDC form has not been received
	≤ 30 days	31-60 days	61-90 days	> 90days		
Newcastle	2 (67%)	1 (33%)	0 (0%)	0 (0%)	3 (100%)	1
Leeds	20 (35%)	9 (16%)	20 (35%)	8 (14%)	57 (100%)	10
Cambridge	7 (23%)	12 (39%)	9 (29%)	3 (10%)	31 (100%)	4
Royal Free	15 (48%)	10 (32%)	5 (16%)	1 (3%)	31 (100%)	5
King's College	33 (20%)	54 (32%)	45 (27%)	35 (21%)	167 (100%)	20
Birmingham	41 (33%)	51 (41%)	29 (24%)	2 (2%)	123 (100%)	15
Edinburgh	25 (48%)	22 (42%)	5 (10%)	0 (0%)	52 (100%)	7
Total	143 (31%)	159 (34%)	113 (24%)	49 (11%)	464 (100%)	62

CONCLUSIONS

- 10 NHSBT have received 19837 SDC forms between 14 December 2017 and 27 April 2025 across all seven UK liver transplant centres. Of the 464 patients on the elective CLD/HCC transplant list on 24 October 2024, 162 (35%) had not had a SDC form returned to NHSBT within the last 2 months and NHSBT had not received any SDC forms for 62 patients who were on the transplant list for more than one month.
- 11 Centres are reminded to send regular updates to NHSBT regarding their patients so that the TBS score accurately reflects the patient's condition.

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