

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 29 April 2024.

METHODS

- 6 Data on all elective SDC forms received by ODT Hub Information Services between 14 December 2017 and 29 April 2024 were extracted from the UK Transplant Registry (UKTR) on 30 April 2024. Data on all patients active on the elective CLD and HCC list and for whom the TBS score was applicable on the 29 April 2024 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 29 April 2024. The number of forms per transplant centre ranged from 444 to 4927 with a median of 1782 SDC forms per transplant centre. Four of the seven transplant centres have submitted a median of two SDC forms per patient.

Transplant centre	No. of SDC forms	No. of patients with returned SDC forms	Median (IQR; range) number of SDC forms per patient
Newcastle	444	142	2 (1, 4; 1, 17)
Leeds	1986	543	2 (1, 4; 1, 27)
Cambridge	1532	471	2 (1, 4; 1, 21)
Royal Free	1647	492	2 (1, 4; 1, 21)
King's College	4864	985	3 (1, 6; 1, 70)
Birmingham	4927	1026	3 (1, 6; 1, 35)
Edinburgh	1782	354	3 (1, 7; 1, 40)
Total	17182	4013	3 (1, 5; 1, 70)

8 Four hundred and eighty nine were active on the elective CLD/HCC transplant list and for whom the TBS score would be applicable on 29 April 2024. 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 169 of 489 patients active on the elective CLD/HCC transplant list. **Table 2** also shows that NHSBT have not received any SDC forms for 68 (14%) patients who had been active on the transplant list for more than 30 days.

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	4 (80%)	1 (20%)	0 (0%)	0 (0%)	5 (100%)	1
Leeds	25 (34%)	29 (39%)	17 (23%)	3 (4%)	74 (100%)	13
Cambridge	21 (44%)	13 (27%)	9 (19%)	5 (10%)	48 (100%)	9
Royal Free	12 (32%)	19 (51%)	4 (11%)	2 (5%)	37 (100%)	6
King's College	42 (30%)	37 (26%)	27 (19%)	34 (24%)	140 (100%)	18
Birmingham	45 (31%)	42 (29%)	40 (28%)	18 (12%)	145 (100%)	16
Edinburgh	20 (50%)	16 (40%)	4 (10%)	0 (0%)	40 (100%)	5
Total	169 (35%)	157 (32%)	101 (21%)	62 (13%)	489 (100%)	68

CONCLUSIONS

- 10 NHSBT have received 17182 SDC forms between 14 December 2017 and 29 April 2024 across all seven UK liver transplant centres. Of the 489 patients on the elective CLD/HCC transplant list on 29 April 2024, 163 (33%) had not had a SDC form returned to NHSBT within the last 2 months and NHSBT had not received any SDC forms for 68 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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