

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 28 April 2019.

METHODS

6 Data on all elective SDC forms received by ODT Hub Information Services between 14 December 2017 and 28 April 2019 were extracted from the UK Transplant Registry (UKTR) on 29 April 2019. Data on all patients active on the elective CLD and HCC list and for whom the TBS score was applicable on the 28 April 2019 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 28 April 2019. The number of forms per transplant centre ranged from 60 to 793 with a median of 366 SDC forms per transplant centre. Six of the seven transplant centres have submitted a median of 2 SDC forms per patient.

Transplant centre	No. of SDC forms	No. of patients with returned SDC forms	Number of SDC forms per patient	
			Median (IQR)	Range
Newcastle	60	33	1 (1, 2)	1, 5
Leeds	459	147	2 (1, 4)	1, 14
Cambridge	287	128	2 (1, 2)	1, 14
Royal Free	361	132	2 (1, 4)	1, 11
King's College	793	257	2 (1, 4)	1, 14
Birmingham	779	260	2 (1, 4)	1, 9
Edinburgh	366	106	2 (1, 5)	1, 14
Total	3105	1063	2 (1, 4)	1, 14

- 8 331 patients were active on the elective CLD/HCC transplant list and for whom the TBS score would be applicable on 28 April 2019. Combined cardiothoracic and liver patients, paediatric, hepatoblastoma and variant syndrome patients were excluded.
- 9 **Table 2** shows that NHSBT have received either an SDC form or a registration form within the last 30 days for 164 of the 331 patients active on the elective CLD/HCC transplant list. **Table 2** also shows that NHSBT have not received any SDC forms for 39 (12%) 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 (21%)	3(16%)	5 (26%)	7 (37%)	19 (100%)	9
Leeds	22 (63%)	10 (29%)	3 (9%)	0 (0%)	35 (100%)	1
Cambridge	15 (48%)	8 (26%)	7 (23%)	1 (3%)	31 (100%)	0
Royal Free	18 (55%)	13 (39%)	2 (6%)	0 (0%)	33 (100%)	4
King's College	39 (45%)	31 (36%)	13 (15%)	3 (3%)	86 (100%)	16
Birmingham	45 (51%)	29 (33%)	11 (13%)	3 (3%)	88 (100%)	4
Edinburgh	21 (54%)	14 (36%)	3 (8%)	1 (3%)	39 (100%)	5
Total	164 (50%)	108 (33%)	44 (13%)	15 (5%)	331	39

CONCLUSIONS

- 10 NHSBT have received 3105 SDC forms between 14 December 2017 and 28 April 2019 across all seven UK liver transplant centres. Of the 331 patients on the elective CLD/HCC transplant list on 28 April 2019, 59 (18%) had not had a SDC form returned to NHSBT within the last 2 months and NHSBT had not received any SDC forms for 39 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.