

NHS BLOOD AND TRANSPLANT

LIVER ADVISORY GROUP

COMPLIANCE WITH SEQUENTIAL DATA COLLECTION SUBMISSION

LAY SUMMARY:

Transplant centres are required to provide NHS Blood & Transplant with accurate and regular information regarding patients who are active on the UK elective liver transplant list in order for patients to be offered livers appropriately. This paper summarises the number of sequential data collection forms received and the time since last sequential form.

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 5 May 2026.

METHODS

6. Data on all elective SDC forms received by ODT Hub Information Services between 14 December 2017 and 5 May 2026 were extracted from the UK Transplant Registry (UKTR) on 24 April 2026. Data on all patients active on the elective CLD and HCC list and for whom the TBS score was applicable on the 5 May 2026 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 5 May 2026. The number of forms per transplant centre ranged from 508 to 6577 with a median of 2545 SDC forms per transplant centre. Four of the seven transplant centres have submitted a median of two SDC forms per patient.
8. **Table 2** shows the number of forms per full calendar year (2018-2025) ranged between 2197 and 3325 with a median of 2716 SDC forms per year.

Table 1 Number of sequential data collection forms received by ODT Hub Information Services, 14 December 2017 to 5 May 2026, 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	508	169	2 (1, 3; 1, 17)
Leeds	2591	715	2 (1, 5; 1, 27)
Cambridge	2028	614	2 (1, 4; 1, 21)
Royal Free	2083	621	2 (1, 4; 1, 21)
King's College	6577	1312	3 (1, 6; 1, 72)
Birmingham	6330	1292	3 (1, 6; 1, 40)
Edinburgh	2545	486	4 (1, 7; 1, 40)
Total	22662	5209	3 (1, 6; 1, 72)

Table 2 Number of sequential data collection forms received by ODT Hub Information Services, 14 December 2017 to 5 May 2026, by transplant centre and year											
Transplant centre	Calendar year										Total
	2017	2018	2019	2020	2021	2022	2023	2024	2025	2026	
Newcastle	16	33	60	104	61	112	54	20	28	20	508
Leeds	48	321	322	289	226	310	359	348	275	93	2591
Cambridge	28	188	225	233	284	272	247	246	211	94	2028
Royal Free	30	257	216	192	325	321	225	231	218	68	2083
King's College	71	542	595	652	730	880	1109	858	898	242	6577
Birmingham	0	564	660	551	864	1009	1003	745	712	222	6330
Edinburgh	0	292	292	275	204	310	328	310	397	137	2545
Total	193	2197	2370	2296	2694	3214	3325	2758	2739	876	22662

- 8 Four hundred and thirty six patients were active on the elective CLD/HCC transplant list and for whom the TBS score would be applicable on 5 May 2026. Combined cardiothoracic and liver patients, paediatric, hepatoblastoma and variant syndrome patients were excluded along with patients not active on the transplant list.
- 9 **Table 3** shows that NHSBT have received either an SDC form or a registration form within the last 30 days for 178 of 436 patients active on the elective CLD/HCC transplant list. **Table 3** also shows that NHSBT have not received any SDC forms for 47 (11%) patients who had been active on the transplant list for more than 30 days.

Table 3 Time since last SDC/registration update for active elective CLD/HCC adults, small adults and large paediatrics, as at 5 May 2026, 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	8 (73%)	2 (18%)	0 (0%)	1 (9%)	11 (100%)	1
Leeds	24 (41%)	16 (28%)	9 (16%)	9 (16%)	58 (100%)	14
Cambridge	24 (59%)	9 (22%)	6 (15%)	2 (5%)	41 (100%)	4
Royal Free	16 (40%)	15 (38%)	7 (18%)	2 (5%)	40 (100%)	8
King's College	34 (27%)	36 (28%)	32 (25%)	26 (20%)	128 (100%)	11
Birmingham	41 (38%)	32 (30%)	25 (23%)	10 (9%)	108 (100%)	8
Edinburgh	31 (62%)	12 (24%)	7 (14%)	0 (0%)	50 (100%)	1
Total	178 (41%)	122 (28%)	86 (20%)	50 (11%)	436 (100%)	47

CONCLUSIONS

- 10 NHSBT have received 22662 SDC forms between 14 December 2017 and 5 May 2026 across all seven UK liver transplant centres. Of the 436 patients active on the elective CLD/HCC transplant list on 5 May 2026, 136 (31%) had not had a SDC form returned to NHSBT within the last 2 months and NHSBT had not received any SDC forms for 47 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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