

The Royal Free Hospital 'Hub-and-spoke' network delivers effective care and increased access to liver transplantation

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Abstract:

Background: “Hub-and-spoke” networks may be one solution to reduce the geographical inequality in access to liver transplantation (LT) and the growing demands on, and saturation of, LT-centres. It is not clear if such networks improve equity of access, deliver comparable patient outcomes or effect patient satisfaction.

Methods: Patient outcomes in those assessed for LT between September 2011 and 2014 at spoke-centres were compared retrospectively with those assessed at the LT hub-centre. Patient satisfaction questionnaires were completed and changes in LT referral patterns were explored with data obtained directly from NHSBT.

Findings: 655 patients (180 spoke; 475 hub) were assessed for LT. Patients referred from spoke centres were more likely to have viral hepatitis as an underlying aetiology (72/180 vs. 110/475; $p<0.001$) or HCC (48/180 vs. 60/475; $p<0.001$) as an indication for LT and were more likely to be listed for LT when compared to hub patients (139/180 vs. 312/475, $p=0.005$). Mortality on the waiting list (9/123 vs. 25/269, $p=0.57$), waiting time to LT (101-days vs. 113-days, $p=0.35$) and MELD/UKELD score ($p=0.24/0.26$) in listed patients were equivalent as were one and three year patient and graft survival rates. Patient satisfaction rates were high at both types of centre, with significantly more patients preferring “locally delivered care” at spoke vs. hub centres ($p<0.0001$). Since the development of formal hub-and-spoke networks data from NHSBT based on postcode confirmed a significant increase in patients undergoing LT (160%) from spoke centres, whereas numbers assessed and transplanted from the hub-centre have remained static.

Interpretation: Hub-and-spoke LT networks are effective in offering equivalent clinical outcomes, high patient satisfaction and alleviate clinical pressure on the hub-centre. They have to potential to help eliminate the geographical disparity in mortality rates from chronic liver disease.

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Introduction

Liver disease in the United Kingdom (UK) is the third commonest cause of premature death with a 400% increase in standardised mortality since the 1970's and remains the glaring exception to the vast improvements made within UK health care over the last 30-years. (1-3) In England and Wales approximately 60,000 patients have cirrhosis, with one and five-year survival rates of just 0.55 and 0.31 respectively for those with a previous liver related hospital admission. (4, 5) There is a significant and worrisome geographical disparity in mortality rates for cirrhosis, such that premature death rates from chronic liver disease in England vary 3.9 fold between primary care trusts. (1, 4) The geographical disparity in liver disease is not limited to mortality, but also access to specialist services, diagnosis and management. In 2014 and 2015 *The Lancet* commission highlighted these issues and proposed strategies to improve outcomes for patients with liver disease, including hub-and-spoke referral pathways to improve access to liver transplantation (LT). (1, 6) It is hoped the engagement of spoke centres via LT will not only improve the geographical disparity in access to LT but also have a secondary effect on improving geographical inequality throughout all aspects of liver disease.

Liver Transplantation is a life-saving, life enhancing procedure for patients with decompensated chronic liver disease (CLD) with survival rates of 90% and 80% at 1- and 5-years respectively. (7) The number of transplants performed annually in the UK is increasing, but lags behind the number needing LT which has more than doubled between 2008 and 2015. (8) A failure to invest in, or to develop, LT services over the last 20-years means LT centres are in a poor position to adapt to increased demand, (9) while the number of LT centres within England (six) remaining static over that time. The current NHSBT 2020 strategy to increase the number of LT performed by 50% by 2020 (by donor optimisation, improved organ offering procedures, policies to encourage organ donation and use of deceased after cardiac death (DCD) organs) raises concerns regarding the capacity of LT centres to cope with the anticipated increase. (9, 10) An additional challenge regarding LT within the UK is that access to LT services is not geographically equitable; LT rates in the UK are highest with geographical proximity LT centres, as opposed to reflecting regions with the greatest disease burden. (4)

Historically, patients being considered for LT are referred to a particular LT centre where pre-transplant optimisation, the LT assessment process, waiting list management, surgery and post-operative care are delivered. It is accepted that the current configuration of LT services in England reflect historical enterprise and

centres were not established with the epidemiology of CLD, geographical variation in disease burden or patient need in mind. (10) Bilateral arrangements between LT and regional centres have been adopted *ad hoc* as a potential solution to improve access and to cope with increased demand using a 'hub and spoke' model, (10) which has proved effective in other conditions including stroke and cancer care. (11-13)

Our view is that established networks with spoke centres defined by need based on patient population and geographical remoteness in conjunction with local and central enthusiasm is the best model to deliver LT with mutual benefits for the hub, spoke and the patient (Table 1). Whilst recommended as a model for LT care, the hub-and-spoke model has not been assessed with regards to outcomes, patient satisfaction or impact on improving geographical access to LT. (6, 10)

The aim of the current study was to determine if LT 'hub-and-spoke' network arrangements delivered equitable clinical outcomes and patient satisfaction when compared to patients managed solely at the hub. Moreover we assessed if access to LT (via number of LT's performed per region over time) increased with the introduction of a hub-and-spoke network.

Patients and Methods

In September 2011, formal network arrangements were established between the RFH and four specialist tertiary liver units (The Royal London Hospital, London (RLH), St Mary's Hospital, London (SMH), The Royal Devon & Exeter, Exeter (RDE) and United Hospitals Bristol, Bristol (UHB)). Patients were defined as managed at the hub alone (RFH) or at one of the four spoke-centres.

Service level agreements (SLA's) for assessment, management on the waiting list and post-operative care were pre-defined; all aspects of pre- and post-operative care, short of LT surgery and immediate post-operative recovery were managed at the spoke-centres with regular outreach sessions provided by RFH physicians. (Figure 1). Data were collected retrospectively on all patients referred and assessed for LT at the RFH between September 2011 and September 2015 and these patients were followed until the censor point in May 2016. Patients referred or transplanted for acute liver failure were excluded. Baseline characteristics were collated (Table 2). Patients were classified as having decompensated CLD if they had a qualifying UKELD score *and* an episode of hepatic decompensation, irrespective of HCC status and patients were classified as having HCC when this was their only indication for LT. Significant clinical outcomes were recorded including listing for

LT, waiting time to LT, death on the waiting list, access to DBD organs and 1- and 3-year patient and graft survival rates were recorded.

Patient satisfaction was assessed at routine post-operative clinic review (supplementary data) in all spoke patients and 50 consecutive hub patients. These focused on patient perception of communication, safety, visibility on the waiting list and overall satisfaction.

Changes in the volume of patients assessed for LT or undergoing LT at the hub or the areas serving the spoke-centres were compared from September 2010 to September 2011 and after formal establishment of the hub-and-spoke networks. NHSBT were contacted to provide complementary geographical data to ensure any increase in activity could be attributable to the network as opposed to re-allocation of activity from other LT centres.

Statistical Analysis:

Data are presented throughout using median and range for numerical values. To determine whether significant differences existed between groups, the Students t test, or the Mann-Whitney-U non-parametric method as appropriate was applied. Differences in nominal data were compiled either by the Chi squared test or using a Fisher's exact test when the number was less than 5 in any given cell of a 2x2 table. A p value of <0.05 was considered to be of statistical significance. Kaplan-Meier curves were constructed to analyse graft and patient survival over time. All statistical analysis was performed using SPSS statistical software package version 21 (SPSS Inc., Chicago, IL).

Results

Assessment for Liver Transplantation

Over the study period 655 patients were assessed for LT; 180 (27%) from spoke-centres and 475 (73%) from the hub. The 179 spoke-centre patients were referred from either the RLH (n=74, 41%), SMH (n=47, 26%), UHB (n=40, 22%) and RDE (n=19, 11%). Hub-patients were either referred from RFH hepatologists (n=170, 36%) or physicians at other centres without formal links established (n=307, 64%).

The indications for assessment overall were decompensated CLD (n=547, 83.5%) with a median MELD/UKELD score of 15/54 or Hepatocellular Carcinoma (HCC) in the absence of hepatic decompensation

(n=108, 16.5%). The commonest underlying aetiologies were alcohol related, hepatitis C related or primary sclerosing cholangitis. A greater proportion of patients from spoke-centres had viral hepatitis as the underlying aetiology (72/180 vs. 110/475; $p<0.001$). A greater proportion of patients were assessed for HCC at spoke vs hub centres (48/180 vs. 60/475; $p<0.001$). Liver disease severity scores in those assessed for decompensated CLD were not statistically different between the hub-and-spoke centres. These data are summarised in Table 2.

Overall 68.9% (n=451) of patients assessed were listed for LT; the primary indication being either decompensated CLD in 82% and HCC in the remainder. Overall, patients from spoke-centres were more likely to be listed for LT than those assessed from the hub (139/180 vs. 312/475, $p=0.005$). Patients from the spoke were more likely to be listed for HCC (36/139 vs 45/312, $p=0.003$) whereas patients from the hub were more likely to be listed for decompensated CLD ($p=0.003$). There were no significant statistical differences between listed hub-and-spoke patients with respect to age, gender and, MELD/UKELD in those listed for decompensated CLD. (Table 2)

The commonest reasons for a patients not being listed for LT following assessment were “too deconditioned/unfit” (n=70, 11%) and “too well” (n=45, 7%); When comparing patients assessed from the spoke-centre vs. hub-centre there was no significant difference in those patients deemed “too deconditioned/unfit” (12/41 vs. 58/163, $p=0.57$) or “too well” (9/41 vs. 36/163, $p=z$).

Waiting list outcomes

There were 451 patients listed for LT comprising 139 (31%) from spoke-centres and 312 (69%) from the hub. A total of 275 (62%) underwent LT; 57 (13%) remain on the waiting list; 59 (13%) were removed from the waiting list and and 34 (7.5%) died awaiting LT. The proportion of patients that died awaiting LT was similar in spoke-centres and the hub (9/123 vs. 25/269, $p=0.57$); the median MELD score (19 vs. 19) and UKELD scores (59 vs. 59) were similar at listing in those that died awaiting LT from the spoke and the hub; the time from listing to death was similar in spoke-centres and the hub (64-days vs 78-days, $p=0.91$). (Table 3)

Transplanted patients

A total of 301/451 (67%) listed patients underwent LT. The likelihood of undergoing LT was similar in spoke-centres and the hub (99/122 vs 202/266, $p=0.30$); waiting times to LT were similar in spoke-centres and

the hub (101-days vs. 113-days, $p=0.35$); DBD organ usage was similar in spoke-centres and the hub (76/99 vs. 154/202, $p=0.87$). Patient survival post LT was similar between the spoke-centres and the hub at 1-year (94/99 vs. 192/202 $p=0.78$) and 3-years (92/99 vs. 186/202 $p=0.78$) (Figure 2a). Graft survival was similar in spoke-centres and the hub at 1-year (93/99 vs. 187/202 $p=0.34$) and 3-years (92/99 vs. 183/202 $p=0.34$) post LT (Figure 2b).

Patient satisfaction

The questionnaire was completed by 74% (73/99) of spoke-centre patients and by 50 consecutive hub patients at their routine post LT clinic visits. Completion rates from the spoke centres were RLH (24/40, 60%), SMH (19/28, 68%), UHB (22/22, 100%) and RDE (8/9, 89%).

Over 90% of patients managed at spoke centres felt there was good bilateral communication between the hub and spoke-centres, 95% did not feel disadvantaged by having their pre- and post-LT care managed away from the hub centre and 96% stated an appreciation for “locally” delivered specialist care. When questioned on reasons for preferring “locally” delivered specialist care; further inquiry revealed the main reasons for preferring “local” specialist care were “familiar hospital/doctor” (87%), “proximity to home/travel time” (81.4%) and “travel cost” (37%). Patient satisfaction with care received at the spoke-centre was ranked at 9.4/10.

Of those surveyed at the hub, the RFH was the patients “local” hospital in 12%. In comparison to spoke-centre patients only 25% of hub patients stated they would have preferred “locally” delivered pre- and post-LT care (11/50 vs. 70/73, $p<0.0001$), with loss of confidence in their local centre being cited as the main reason. The reasons stated for a preference for “local” care were travel time and cost (75% 8/11) with only 27% (3/11) stating familiarity as a reason. Overall satisfaction with care received at the hub was ranked at 9.4 out of 10.

Improving access to LT: historical comparison

In the year prior to formal hub-and-spoke networks being established there were 18 patients assessed of which 9 were transplanted from geographical areas served by prospective spoke centres. Since the formal hub-and-spoke networks were introduced in 2011 there has been on average a 120% increase in patients assessed and a 160% increase in patient undergoing LT from the spoke centres. In comparison at the hub-centre there has been a 12% increase in patients assessed and a 9% reduction in patients undergoing LT. Data direct from NHSBT on the number of transplants performed in designated “hub” catchment areas was obtained from 2009 – 2015. This confirmed an average increase of 154% in transplant activity since the development of Hub centres. (14)

Discussion

In this study we have demonstrated for the first time that LT care delivered via hub-and-spoke networks is effective with equitable clinical outcomes regarding waiting times for LT, organ utilisation and, 1- and 3-year graft and patient survival rates. Moreover we have shown that patient satisfaction with “locally delivered specialist care” is excellent and that geographical access to LT for patients has increased significantly since the advent of such networks in regions served by dedicated spoke-centres.

An anxiety and perhaps reticence of some LT centres/physicians towards the hub-and-spoke network is that LT waiting list patients could be disadvantaged via a “lack of expertise” and “lack of visibility” to the transplanting hub-centre, resulting in a longer wait for LT and higher wait-list mortality. This study has shown no difference in waiting list mortality ($p=0.57$), wait for LT ($p=0.35$), LT rates ($p=0.3$) and delisting rates ($p=0.51$) when comparing hub-and-spoke patients. The equity between centres is likely to reflect equivalent clinical care provided by motivated spoke physicians and the robust communication networks in place between all our hub-and-spoke centres. Devolving post-LT management largely to spoke-centres is likely to cause similar anxieties amongst some LT centres/physicians with regards to inferior experience and expertise in the management of post-LT complications at spoke-centres. This study has shown these anxieties not to be borne out with equivalent 1- and 3-year graft and patient survival in hub-and-spoke centres. Less robust clinical endpoints which may reflect the more subtle nuances of the quality of post-LT care such as renal

function, cardiovascular, infectious and malignant complications have yet to be evaluated between hub-and-spoke centres but are additional important future parameters which should be assessed in ensuring equivalence. (15)

Our study has highlighted some important differences between the hub-and-spoke centres. Firstly patients from spoke-centres were significantly more likely to be listed for (139/180 vs. 312/475, $p=0.005$), and have HCC as an indication for (36/139 vs. 45/312, $p=0.003$) LT. One may argue that the difference in likelihood of being listed may be a reflection of spoke-centres referring in only “cast iron cases”. However no significant difference in assessed patients MELD/UKLED scores in decompensated CLD ($p=0.24/0.26$), age ($p=0.49$) or those deemed too deconditioned for LT ($p=0.57$) was noted suggesting case mix is similar. The differences the proportion listed between hub-and-spoke centres is likely to reflect subtle difference in the assessment process. Patients being considered for LT at spoke-centres undergo initial screening assessment investigations (echocardiography, pulmonary function tests, computed tomography, exercise testing etc) and are discussed in principle with the hub-centre before a formal LT assessment is commenced, thus ruling out early those patients with prohibitive co-morbidities; whereas at the spoke centre potential LT patients are admitted for a 5-day assessment where all LT assessment investigations are performed and then the patient is formally discussed in the listing meeting at the end of the week, and those with prohibitive comorbidities declined. The difference in HCC as an indication for LT between the hub and spoke-centre is more difficult to explain. It may reflect geographical differences in aetiology as viral hepatitis (a strong risk factor for HCC) was also significantly higher in the spoke population ($p<0.001$).

The second difference worthy of discussion is that although patient satisfaction with the LT process was high at both the hub-and-spoke centres (ranked 9.4/10), patients at spoke-centres valued a familiar hospital/doctor (87%) as a reason for “local” care and 98.4% reported “feeling safe” being managed by their local centre. Conversely hub-patients cited a lack of confidence in their “local” centre for preferring care delivered centrally at the hub. These differences, although not evaluated in this study, are likely to be multifactorial with many contributing factors including; highly engaged and motivated spoke physicians, ongoing dialogue between spoke and hub physicians via regular out-reach clinics, the presence of a RFH physician at spoke out-reach clinics, financial investment in spoke centres via SLA’s alongside possible

disengagement of non-spoke local physicians due to a perception of a loss of autonomy in the management of their patient and finally less robust communication pathways between non-spoke local centres and the RFH.

Spoke-centres should be established where there is a clinical need either secondary to geographical remoteness or due need based on patient population density. (6, 10) In this study two of our spoke-centres (RLH and SMH) were established based on high patient populations with CLD and both are within an 8-mile radius of the hub-centre, whereas the remaining two centres (UHB and RDE) were established due to geographical remoteness being 120- and 170-miles from the hub-centre respectively. Despite differences in patient volume and distance from the LT-hub a sub-analysis of outcomes between the centres reassuringly showed no significant differences indicating that both indications for a spoke centre are valid and effective. (Supplementary data: table 1)

Finally we have shown an increase of 160% in transplant activity from hub centres, since the development of networks. It could be argued that this increase in activity merely reflects taking activity away from other LT centres and is not due to improved geographical access to LT. Data obtained direct from NHSBT however on number of transplants based on postcode has also shown a similar increase (154%) in activity since the setting up of the RFH networks. (14) This strongly adds weight to the hypothesis that the increase in activity is due to improved access to LT offered by the networks, as opposed to re-allocation of activity between LT centres.

The study does have limitations which highlight areas for future exploration. Firstly with regards to patient satisfaction only post-LT patients were evaluated, not those who remained on the LT waiting list or had been delisted. Clearly these are sub-sets of patients at different stages in the LT process and their satisfaction and perception of the care they are receiving could differ. Secondly the RFH has 2 additional outreach centres (which contributed to 5.6% (17/301) of the total number transplanted) where the LT assessment process / post LT management is a "half way house" between fully devolved spoke-care and unilateral hub-care. For the purpose of the study due to a lack of provision for pre transplant assessment within the SLA and some networks only recently formed these patients were classed as belonging to the hub-centre and potentially could have skewed our results. It remains to be evaluated if this model is cost effective or improves inequality in other aspects of service delivery in liver disease.

In conclusion hub-and-spoke LT networks are effective offering equivalent clinical outcomes for patients, with high patient satisfaction scores, alleviate clinical pressures on the hub-centre and have the potential to contribute to eliminating the geographical imbalance between mortality rates, service provision and clinical need in patients with advanced chronic liver disease.

Table 1: Potential benefits of hub-and-spoke delivery of LT care throughout the UK

Patient	Hub	Spoke
Care delivered locally	Growth of transplant activity	Empowerment / service development
Potential to improve equity of access to LT	Foster closer working relationships with referrers	Formal referral pathways
Long-term continuity of care	Reduce pressure on resources	Research and education

Table 2: Patient data (a) assessed and (b) listed for LT from hub and spoke centres (* p<0.05)

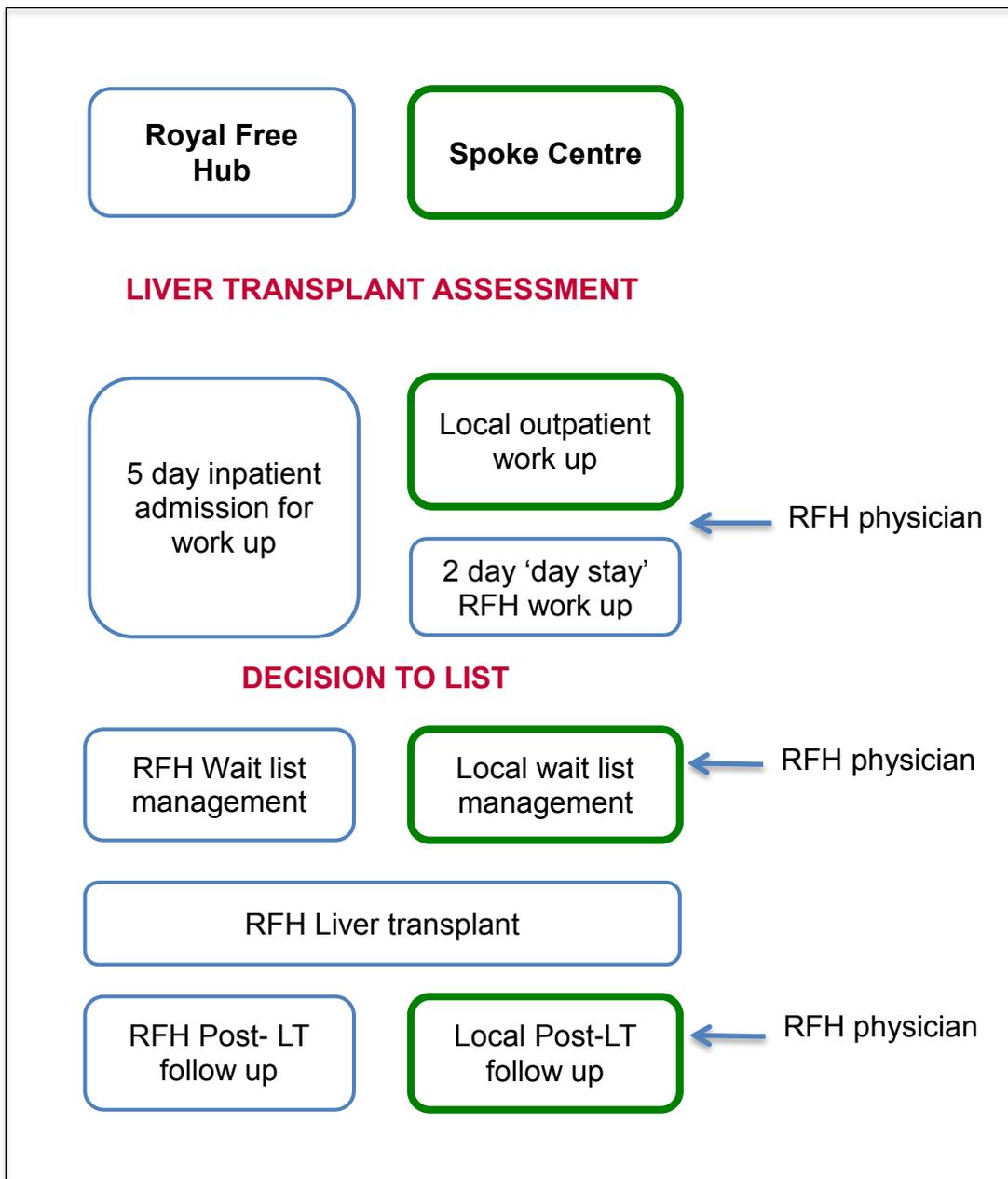
(a)	Overall	Spoke	Hub	Spoke vs Hub (p value)	
Patients, n	655	180	475	-	
Gender, m/f, n (%)	451/204 (68.9/31.1)	132/48 (73.3/26.7)	319/156 (67.2/32.8)	0.13	
Age, median, (range), years	57 (17-74)	56 (17-73)	57 (19-74)	0.49	
Aetiology					
ALD, n (%)	207 (31.6)	51 (28.3)	156(32.8)	<0.05	
HCV, n (%)	144 (22)	55 (30.6)	89 (18.7)		
PSC, n (%)	70 (10.7)	19 (10.6)	51 (10.7)		
NAFLD, n (%)	58 (8.9)	15 (8.3)	43 (9.1)		
AIH, n (%)	40 (6.1)	8 (4.4)	32 (6.7)		
HBV, n (%)	38 (5.8)	17 (9.4)	21 (4.4)		<0.05
PBC, n (%)	35 (5.3)	6 (3.3)	29 (6.1)		
Other, n (%)	58 (9)	9 (5)	49 (10)		
Indication DCLD/HCC, n (%)	547/108 (83.7/16.4)	132/48 (73.3/26.7)	415/60 (87.4/12.6)	<0.0001*	
MELD (DCLD), median, (range)	15 (6-52)	15 (6-45)	15 (6-52)	0.24	
UKELD (DCLD), median, (range)	54 (0-80)	55 (0-67)	54 (0-80)	0.26	

(b)	Overall	Spoke	Hub	Spoke vs Hub (p value)
Patients, n	451	139	312	-
Gender, m/f, n (%)	319/132 (70.7/29.3)	101/38 (72.7/27.3)	218/94 (69.9/30.1)	0.57
Age, median, (range), years	56 (17-74)	55 (17-73)	57 (19-74)	0.82
Aetiology				
ALD, n (%)	124 (27.5)	40 (28.8)	84 (26.9)	
HCV, n (%)	111 (24.6)	44 (31.7)	67 (21.5)	
PSC, n (%)	52 (11.5)	16 (11.5)	36 (11.5)	
NAFLD, n (%)	35 (7.8)	8 (5.8)	27 (8.7)	
AIH, n (%)	33 (7.3)	7 (5.0)	26 (8.3)	
HBV, n (%)	29 (6.4)	14 (10.1)	15 (4.8)	
PBC, n (%)	22 (4.9)	5 (3.6)	17 (5.4)	
Other, n (%)	45 (10)	5 (4)	40 (12)	
Indication DCLD/HCC, n (%)	370/81 (82.0/18.0)	103/36 (74.1/25.9)	267/45 (85.6/14.4)	0.003*
MELD (DCLD), median, (range)	15 (6-44)	16 (7-32)	15 (6-44)	0.18
UKELD (DCLD), median, (range)	55 (7-74)	55 (43-67)	54 (7-74)	0.92

Table 3: Outcomes for patients listed for transplantation (* p<0.05)

	Overall	Spoke	Hub	Spoke vs Hub p value
Listed, n (% assessed)	451 (68.9)	139 (77.2)	312 (65.7)	0.005*
Delisted, n (%)	59 (13.1)	16 (11.5)	43 (13.8)	0.61
Deconditioned, n (% of delisted)	20 (33.9)	5 (31.3)	15 (34.9)	
Re-compensation, n (% of delisted)	16 (27.1)	3 (18.8)	13 (30.2)	
Progression outside HCC criteria, n (% of delisted)	11 (18.6)	5 (31.3)	6 (14.0)	
Breaking patient contract, n (% of delisted)	9 (1.4)	2 (12.5)	7 (16.3)	
Patient choice, n (% of delisted)	3 (0.5)	1 (6.3)	2 (4.7)	
Transplanted, n (% on WL)	301 (76.8)	99 (80.5)	202 (75.1)	0.30
DBD organ, n (% transplanted)	230 (76.4)	76 (76.8)	154 (76.2)	0.87
Time from listing to transplant, median (range), days	106 (1-1107)	101 (1-616)	113 (1-1107)	0.35
Still waiting, n(% on WL)	57 (12.6)	15 (12.2)	42 (20.8)	0.37
Died on WL, n(%)	34 (7.5)	9 (7.0)	25 (9.3)	0.57
MELD, median (range)	19 (8-36)	19 (14-32)	19 (8-36)	0.71
UKELD, median (range)	59 (48-72)	59 (50-67)	59 (48-72)	0.96
Time from listing to death, median (range), days	78 (8-960)	64 (8-607)	79 (13-960)	0.91

Figure 1: Flow chart highlighting LT patient pathway for hub-and-spoke patients



Supplementary data: Spoke centre analysis (* p<0.05)

	Overall Spoke	St Marys	RLH	RD&E	UHB	Sub group p value
Patients, n	180	48	74	18	40	-
Gender m/f, n(%)	132/48 (73.3/26.7)	11/37 (22.9/77.1)	25/49 (33.8/66.2)	4/14 (22.2/77.8)	8/32 (20.0/80.0)	0.34
Age, median (range), years	56 (17-73)	56 (17-74)	55 (17-73)	57 (19-74)	54 (23-71)	
Aetiology						0.013*
ALD n(%)	51 (28.3)	10 (20.8)	12 (16.2)	12 (66.7)	17 (42.5)	*
HCV n(%)	55 (30.6)	18 (37.5)	23 (31.1)	3 (16.7)	11 (27.5)	
PSC n(%)	19 (10.6)	8 (16.7)	8 (10.8)	0 (0.0)	3 (7.5)	
NAFLD n(%)	15 (8.3)	2 (4.2)	7 (9.5)	3 (16.7)	3 (7.5)	
AIH n(%)	8 (4.4)	0 (0.0)	7 (9.5)	0 (0.0)	1 (2.5)	
HBV n(%)	17 (9.4)	6 (12.5)	11 (14.9)	0 (0.0)	0 (0.0)	
PBC n(%)	6 (3.3)	3 (6.3)	1 (1.4)	0 (0.0)	3 (7.5)	
Non cirrhotic indication n(%)	2 (1.1)	0 (0.0)	1 (1.4)	0 (0.0)	1 (2.5)	
Post OLT ind n(%)	2 (1.1)	0 (0.0)	1(1.4)	0 (0.0)	0 (0.0)	
Cryptogenic n(%)	1 (0.6)	1 (2.1)	1 (1.4)	0 (0.0)	1 (2.5)	
Metabolic n(%)	1 (0.6)	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.5)	
Other n(%)	3 (1.7)	0 (0.0)	2 (2.7)	0 (0.0)	1 (2.5)	
Indication	132/48 (73.3/26.7)	35/13 (72.9)	55/19 (74.3)	15 (83.3)	27/13 (67.5)	0.65
DCLD/HCC n, (% DCLD)						
MELD (DCLD), median, (range)	15 (6-45)	14 (6-30)	14 (7-31)	18 (11-25)	16 (7-40)	0.87
UKELD (DCLD), median, (range)	55 (0-67)	54 (48-65)	54 (45-67)	58 (0-65)	55 (43-67)	0.21
Listed, n (% assessed)	139 (77.2)	36 (75.0)	60 (81.1)	14 (77.8)	29 (72.5)	0.74
Delisted, n (% listed)	16 (11.5)	3 (8.3)	8 (13.3)	1 (7.1)	4 (13.8)	0.1
Deconditioned, n (% of delisted)	5 (31.3)	0 (0.0)	4 (50.0)	0 (0.0)	1 (25.0)	
Re-compensation, n (% of delisted)	3 (18.8)	0 (0.0)	1 (12.5)	1 (100)	1 (25.0)	
Progression outside HCC criteria, n (% of delisted)	5 (31.3)	1 (33.3)	3 (37.5)	0 (0.0)	1 (25.0)	
Breaking patient contract, n (% of delisted)	2 (12.5)	2 (66.7)	0 (0.0)	0 (0.0)	0 (0.0)	
Patient choice, n (% of delisted)	1 (6.3)	0 (0.0)	0 (0.0)	0 (0.0)	1 (25.0)	
Transplanted, n (% on WL)	99 (80.5)	29 (87.9)	43 (84.3)	9 (69.2)	18 (72.0)	0.27
DBD organ, n (% transplanted)	76 (76.8)	20 (69.0)	31 (72.1)	9 (100)	16 (89.0)	0.38

Time from listing to transplant, median (range), days	101 (1-616)	77 (1-616)	101 (9-588)	169 (8-361)	144 (15-562)	0.28
Still waiting, n (% on WL)	15 (12.2)	2 (6.1)	6 (11.5)	1 (7.7)	6 (24.0)	0.2
Died on WL, n (% on WL)	9 (7.0)	2 (6.0)	3 (5.8)	3 (23.1)	1 (4.0)	0.14
MELD, median (range)	19 (14-32)	19 (17-20)	16 (14-20)	19 (15-19)	32	0.29
UKELD, median (range)	59 (50-67)	58 (56-60)	59 (50-62)	59 (56-65)	67	0.67
Time from listing to death, median (range), days	64 (8-607)	147 (20-274)	20 (62-607)	64 (52-87)	37	0.67

Supplementary data: Questionnaire

Telephone interview with post-transplant patients through at spoke-centres

Did you feel there was good communication between the satellite liver transplant unit and the transplant centre?

Yes definitely [] Yes to some extent [] No []

Did you appreciate your pre-transplant care being delivered locally?

Yes [] No []

If so, please rank in order the top three reasons you appreciated about being managed in Bristol Royal Infirmary?

- | | |
|---------------------------------------|-----------|
| 1. Near Home | [] |
| 2. Time travelling to London | [] |
| 3. Cost of travelling to London | [] |
| 4. Being in a familiar hospital | [] |
| 5. Being managed by a familiar doctor | [] |
| 6. Other | [_____] |

Did you feel disadvantaged when waiting for a transplant by not being managed directly by the Royal Free?

Yes, definitely [] Yes to some extent [] No []

If so, what was the reason you felt disadvantaged?

Did you feel safe following discharge from the Royal Free, to have your care managed by Bristol Royal Infirmary?

Yes, definitely [] Yes to some extent [] No []

Overall how would you rate your satisfaction with the liver transplantation service delivered between Bristol Royal Infirmary and the Royal Free Hospital?

Rank 1 (poor) – 10 (excellent) []

Any other comments?

Appendix 1: (b) Telephone interview with post-transplant patients at hub centre

Did you feel there was good communication between the liver transplant team and yourselves?

Yes definitely [] Yes to some extent [] No []

If your pre-transplant care could be delivered at your local hospital, would you prefer this?

Yes [] No []

If so, please rank in order the top three reasons you would prefer to be managed at your local hospital?

- | | |
|--|-----------|
| 7. Near Home | [] |
| 8. Time travelling to London | [] |
| 9. Cost of travelling to London | [] |
| 10. Being in a familiar hospital | [] |
| 11. Being managed by a familiar doctor | [] |
| 12. Other | [_____] |

If not, why not?

Overall how would you rate your satisfaction with the liver transplantation service at the Royal Free Hospital?

Rank 1 (poor) – 10 (excellent) []

Any other comments?

References:

1. Williams R, Aspinall R, Bellis M, Camps-Walsh G, Cramp M, Dhawan A, et al. Addressing liver disease in the UK: a blueprint for attaining excellence in health care and reducing premature mortality from lifestyle issues of excess consumption of alcohol, obesity, and viral hepatitis. *Lancet*. 2014;384(9958):1953-97.
2. World Health Organization regional office for Europe. European health for all database (HFA-DB). 2014. <http://data.euro.who.int/hfadbf/> (accessed June 4).
3. Office for National Statistics. Mortality statistics: deaths registered in England and Wales (series DR) N, UK: Office for National Statistics; 2011.
4. <http://www.rightcare.nhs.uk/index.php/atlas/liver-disease-nhs-atlas-of-variation-in-healthcare-for-people-with-liver-disease>. NHSRCLDtNaovihfpwld.
5. Ratib S, Fleming KM, Crooks CJ, Aithal GP, West J. 1 and 5 year survival estimates for people with cirrhosis of the liver in England, 1998-2009: a large population study. *Journal of hepatology*. 2014;60(2):282-9.
6. Williams R, Ashton K, Aspinall R, Bellis MA, Bosanquet J, Cramp ME, et al. Implementation of the Lancet Standing Commission on Liver Disease in the UK. *Lancet*. 2015;386(10008):2098-111.
7. Neuberger J. Liver transplantation in the United Kingdom. Liver transplantation : official publication of the American Association for the Study of Liver Diseases and the International Liver Transplantation Society. 2016.
8. Martin K AE, Johnson R (2015) Annual report on liver transplantation: report for 2014/2015, NHS Blood and Transplant, accessed at http://www.odt.nhs.uk/pdf/organ_specific_report_liver_2015.pdf.
9. www.nhsbt.nhs.uk/to2020. NHSBaTTott.
10. O'Grady JG. Network and satellite arrangements in liver disease. *Frontline Gastroenterol*. 2013;4(3):187-90.
11. Darzi L. High Quality Care For All – NHS Next Stage Review Final Report 5.
12. Agarwal S, Day DJ, Sibson L, Barry PJ, Collas D, Metcalf K, et al. Thrombolysis delivery by a regional telestroke network--experience from the U.K. National Health Service. *J Am Heart Assoc*. 2014;3(1):e000408.
13. Khakwani A, Rich AL, Powell HA, Tata LJ, Stanley RA, Baldwin DR, et al. The impact of the 'hub and spoke' model of care for lung cancer and equitable access to surgery. *Thorax*. 2015;70(2):146-51.
14. Data obtained directly from Mark Jones SS, Statistics & Clinical Studies, NHS Blood and Transplant.
15. EASL Clinical Practice Guidelines: Liver transplantation. *Journal of hepatology*. 2016;64(2):433-85.