# NHS BLOOD AND TRANSPLANT
# ORGAN AND TISSUE DONATION AND TRANSPLANTATION

## THE FORTY FOURTH MEETING OF THE LIVER ADVISORY GROUP AT 11:00 AM ON 24 MAY 2023
**VIA MS TEAMS**

## MINUTES

**ATTENDEES:**

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| Douglas Thorburn | Chair, Liver Advisory Group / Royal Free Hospital |
| Anya Adair | Royal Infirmary of Edinburgh |
| Michael Allison | Addenbrookes, Hospital, Cambridge |
| Varuna Aluvihare | Kings College Hospital, London |
| Sarah Banks | Recipient Co-ordinator Representative |
| Racquel Beckford | King's College Hospital, London |
| Will Bernal | King's College Hospital, London |
| Helen Bullock | Product Owner, NHSBT |
| Lisa Burnapp | AMD for Living Donation and Transplantation, NHSBT |
| Lee Claridge | St James's University Hospital |
| Matthew Cramp | University Hospitals Plymouth/BLTG Representative |
| Audrey Dillon | St Vincent's Hospital, Dublin |
| Paul Gibbs | Addenbrookes Hospital, Cambridge |
| Tassos Grammatikopoulos | King's College Hospital, London |
| Vanessa Hebditch | Chief Executive, British Liver Trust |
| Emir Hoti | St Vincent's Hospital Dublin |
| John Isaac | Deputy Chair LAG / University Hospitals, Birmingham |
| Maria Jacobs | Statistics & Clinical Research, NHSBT |
| Rebeka Jenkins | Clinical Research, NHSBT |
| Andrew Madden | Lay Member |
| Derek Manas | Medical Director, OTDT, NHSBT |
| Steven Masson | The Freeman Hospital, Newcastle upon Tyne |
| Krishna Menon | Kings College Hospital, London |
| Marumbo Mtegha | Paediatric representative, Leeds Teaching Hospital |
| David Nasralla | Royal Free Hospital, London |
| Thamara Perera | University Hospitals, Birmingham |
| Suzie Phillips | Statistics & Clinical Research, NHSBT |
| Joerg-Matthias Pollok | Royal Free Hospital, London |
| Raj Prasad | Previous National Liver Clinical Lead for Utilisation |
| Peter Robinson-Smith | Recipient Co-ordinator Representative |
| Ian Rowe | Chair of the National Liver Offering Scheme Monitoring Committee |
| Khalid Sharif | University Hospitals, Birmingham |
| Ken Simpson | Royal Infirmary of Edinburgh |
| Sanjay Sinha | National Surgical Lead, Clinical Governance, NHSBT |
| Laura Stamp | Lead Nurse Recipient Coordinator, NHSBT |
| Rhiannon Taylor | Statistics and Clinical Research, NHSBT |
| Chris Watson | University of Cambridge |
| Gwilym Webb | Addenbrookes Hospital, Cambridge |
| Rachel Westbrook | Royal Free Hospital, London |
| Steve White | PAG Chair/ The Freeman Hospital, Newcastle upon Tyne |
| Julie Whitney | Head of Service Delivery - ODT Hub, NHSBT |
| Michelle Wilkins | Head of Services, CLDF |

## IN ATTENDANCE:

Cherrelle Francis-Smith, Medical Director and Group Support, NHSBT
Alicia Jakeman, Medical Director and Group Support, NHSBT
Harry Spiers, Observer, Addenbrookes Hospital, Cambridge

## APOLOGIES:

Becky Clarke, Ian Currie, Rebecca Cooper, Pam Healy, Aileen Marshall, Michael Stokes, Lynne Vernon, Sarah Watson

| | Item | Action |
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| **1** | **Declarations of interest** | |
| | There were no declarations of interest. | |
| **2.** | **Minutes of the last Meeting, held on 02 November 2022 - LAG(M)(22)02** | |
| **2.1** | **Accuracy**<br>There were no issues of accuracy raised. | |
| **2.2** | **Action Points – LAG(AP)(22)2**<br>**AP6 Colorectal liver metastases**<br>K Menon updated the group, advising that the audit has been sent to centres, referrals are coming in. To be discussed in November LAG meeting.<br>**AP7 Cholangiocarcinoma**<br>J Isaac advised that a lot of progress has been made, to go to NHSE later this year as a pre-commissioned study. | **K Menon** |
| **2.3** | **Matters Arising, not separately identified**<br>There were no matters arising | |
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| **3.** | **Medical Director's Report** | |
| **3.1** | **Organ and Tissue Donation and Transplantation (OTDT) Update** | |
| | D Manas provided an OTDT update:<br>The Lead Clinical Lead for Utilisation (CLU) advert has gone out.<br>The Lead CLUs are funded, local CLUs are not funded. A business case has gone to the Department of Health. The Organ utilisation Group (OUG) report stated that their funding is the responsibility of their local Trust.<br>The OUG Report came out in February 2023 with 12 recommendations.<br>DCD hearts will be funded for the next year.<br>NRP & Machine Perfusion funding cases have been submitted.<br>The current National Organ Retrieval Services (NORS) arrangements will be reviewed.<br>A lung summit was held due to poor utilisation, with 18 recommendations, however utilisation has now improved.<br>Consent this month was 76%, the highest rate yet, with consent from ethnic minorities at 56%.<br>There are no CUSUM signals currently under investigation.<br>TransplantPath, the EOS replacement, will be live from Winter 2023.<br>Corneal donation is at an all-time low with 6000 patients waiting.<br>The UW solution issue is ongoing.<br>The OUG recommended that the assessment and recovery centres (ARCs) are to be developed, with the FTWG to look at what the liver community would like.<br>The IT changes that are awaiting have been escalated to the NHSBT Executive Team.<br>A formal review of the principles and fundamentals of NLOS will commence shortly, having been agreed by the Executive Team.<br>V Aluvihare asked if D Manas felt that NORS is delivering, D Manas advised that the transplant process has become prolonged and will therefore be reviewed. This review will take place as soon as possible.<br>Trust funding and renumeration was discussed, with specialised commissioning services falling under block funding sent directly to Trusts.<br>J Isaac asked if NHSBT could do something to ensure that the funding is given directly to the transplant services. The current funding model does not cover work-up when patients are being transplanted at other centres.<br>D Manas advised that Commissioners have advised that a Service Level Agreement will need to be created for this, but NHSBT continue to push for 25% to be invested back into NHSBT. S Sinha advised that collaborating | |

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| | kidney centres have a SLA for the second centre reimbursed by the patients local centre.<br>S Sinha asked if NORS contracts could be changed due to the change in number of retrievals by centres. D Manas advised that a contract review meeting should be held in each centre with some doing more retrievals than others. The Clinical Lead should raise this in their centre's meeting. | |
| **3.2** | **Overseas travel for transplantation** | |
| | L Burnapp advised members that herself and M Robb, Lead Statistician for kidney transplantation, NHSBT are the national focal points within the Council of Europe for auditing travel for transplantation. This covers both people going outside the UK to receive a transplant and those who wish to seek a transplant in the UK. She highlighted the recent high-profile case that was being prosecuted under the Modern Slavery Act, raising a number of issues around safeguarding. The HTA and Department of Health will make recommendations to Ministers, with new guidance by the end of 2023.<br>Any concerns about travel for transplantation should be emailed to; transplants@HTA.gov.uk | |
| **3.3** | **Liver Utilisation Report (Waiting list dynamic) for noting - LAG(23)01** | |
| | D Thorburn advised that this report is generated monthly for the Liver Centre Director's meeting. There is a 10% reduction in the number of donors, predominantly in DBD donors with a 5% reduction in liver transplant activity. There is subsequently a substantial rise in the size of the waiting list. However, DBD transplantation should hopefully increase due to the increasing consent rates. | |
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| **4.** | **Liver Transplant Commissioning** | |
| **4.1** | **NHS England** | |
| | S Watson was not present at the meeting. | |
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| **5.** | **Update on the National Liver Offering Scheme (NLOS)** | |
| **5.1** | **Benefit realisation on the National Liver Offering Scheme** | |
| **5.1.1** | **60 month data and 5 month review - LAG(23)03, LAG(23)04** | |
| | I Rowe provided an update on the review of NLOS, with waiting list mortality signalling whether the scheme is working:<br>The paper detailed that outcomes have improved in terms of waiting list mortality.<br>There is variation between centres whether livers are accepted and transplanted or declined and whether they accept named patient offers.<br>Following the updates, the number of offers made to certain aetiologies have decreased. The Committee will continue monitoring on a 6 monthly basis, following the updates to the parameters to see whether there is a sustained impact in those groups.<br>DCD livers numbers are higher now for Variant Syndrome patients.<br>K Menon asked if this could be due to decreased DBD donation and increased DCD donation. D Thorburn confirmed that this will be looked at in more detail and could be due to a number of factors.<br>Post-transplant survival remains good for both DBD and DCD organs, one year survival for DCD outcomes is over 95%. | **R Taylor** |
| **5.1.2** | **Summary Feedback of key points from NLOS - LAG(23)04** | |
| **5.1.3** | **Impact of NLOS on patients on the list during the first 60 months - LAG(23)05** | |
| | I Rowe advised that there has been a sequence of queries where it is felt that patients are being disadvantaged by NLOS. This paper details that removals from the waiting list for patients who died or their condition deteriorated runs at about 10% overall, it was 9% last year.<br>A number of centres and patient support charities for PSC have concerns that they're being disadvantaged. However, the data shows that PSC patients have amongst the lowest mortality rates.<br>In terms of mortality amongst patients by age group, the lowest mortalities are in the 17-to-25-year age group, the highest mortality is in patients aged over 50-to-59 and 60 plus. The paper details the proportion of patients who died or were removed from the waiting list, having received zero offers.<br>D Thorburn queried the difference in waiting list mortalities over centres and asked if this could be triangulated with acceptance rates by centres. | |

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| | It was agreed that NLOS appeared to have delivered on its intended purpose. It was proposed that this information could be generated in a patient friendly format such as an infographic to demonstrate the impact of NLOS. | **R Taylor/ LAG Core Group** |
| **5.2** | **Refinements to NLOS (High weight, High INR, Inpatient status) - LAG(23)06** | |
| | R Taylor presented the information on data entered on the patients' registration forms or sequential updates used to determine a patients transplant benefit score (TBS.) She advised of delays by centres to provide data impacts on a patient's position in the offering sequence.<br>Centres have reported that patients weighing over 100kg had been registered at 100kg weight to ensure they received an appropriate offer. It has been fedback to centres that accurate weights should be recorded; it will be further investigated whether the weight ranges should be applied to all weight groups.<br>Recipient INR data was also reviewed, to review if the adjusted or actual value was being recorded for patients on Warfarin.<br>The impact of patient location on the TBS score was also reviewed, following concerns raised. Having been reviewed by NLOS and LAG Core Group (LAGCG) on May 10th & 11th a letter was sent to centres on May 12th to ask all patients to be listed as outpatients. This was redacted on 26th May and centres were asked to report the true patient location. The impact of this review will be monitored by NHSBT and reported at November's LAG meeting.<br>Centres were reminded that any concern should be emailed to the Chairs of NLOS monitoring committee and LAG and correct information should always be reported to NHSBT for data integrity.<br>It was agreed the formal process of reviewing centre concerns should be documented. | **R Taylor**<br><br>**R Taylor**<br><br>**A Mason/ D Thorburn/ I Rowe** |
| **5.3** | **Flight costs and blue light - LAG(23)07 - for noting** | |
| | D Thorburn highlighted the cost of flights for organs accepted for the purpose of splitting despite there being a paediatric centre geographically closer. Centres should each examine the number of flights they used where the estimated drive time was less than 5 hours.<br>No further points were raised for discussion. | **All Centres** |
| **5.4** | **Compliance with Sequential Data Submission - LAG(23)02 - for noting** | |
| | There was no discussion on this paper, for noting. | |
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| **6.** | **Update from FTWUs** | |
| **6.1** | **Monitoring of new service evaluations and HPS pathway - LAG(23)09** | |
| | D Thorburn advised that time waited on the variant list was evaluated, with this paper detailing the number of patients referred through the service evaluations:<br>One registration has been made to the NET pathway, with the programme being open for over a year. Many more patients have been discussed in the MDT and are still being considered for listing.<br>The Intrahepatic Cholangiocarcinoma pathway is open, with one patient registered, having been open for six months.<br>With Colorectal Mets, the panel have been approached for one patient to be registered but this was declined.<br>There have been 16 HPS patients referred, all accepted, with 5 transplanted. One patient was deemed severe (PaO2 on air less than 8kPa) and has received a transplant in November 2022.of the nine patients active, four have appeared on no matching runs. Their waiting times continue to be reviewed, if waiting longer than three months on the waiting list. Centre representatives were reminded they should provide a regular (3 monthly) update on the PaO2 sitting on air for these patients. | **Centre Reps.** |
| **6.2** | **ACLF - LAG(23)11** | |

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| | W Bernal provided the group with a learning summary of the programme, with the ACLF paper distributed to members.<br>The survival rate for those transplanted is 78%. There is approximately one patient registered per month, 8 (22%) did not receive a transplant and sadly all died at a mean of 13 days after registration.<br>The appendix summarises trends that have been identified, predicting mortality for this patient group.<br>D Thorburn advised that the outcomes for the most recent cohort transplanted are worse than previous patients. V Aluvihare asked if there should be exclusion criteria defined. W Bernal advised that after the 50 cases, this could include age, severity of illness, anticipated surgical complexity and waiting time.<br>G Webb asked if the data on the geography of the patients; their location compared with centres and the referral process has been analysed.<br>W Bernal confirmed that this data has not yet been looked at but can do this using their post code and will be taken up off-line. | **W Bernal/ R Taylor** |
| **6.3** | **Machine Perfusion report - LAG(23)10, LAG(23)10b - for noting** | |
| | C Watson advised that the group meet two-monthly to look at cases that have not gone well, where some transplants do well in some recipients and not others. The outcome data will be reviewed when this is received, including graft failure. The data collection form was introduced in October 2022 with the outcome data on short-term survival now being received.<br>C Watson advised that the FTWG looking at governance and drafting guidelines meet two-monthly, when further data is received this will be analysed and will refine the guidance in an evidence-based way. | |
| **6.4** | **HCV positive transplants into HCV negative recipients - LAG(23)12 - for noting** | |
| | D Thorburn advised that there have been eight organs that have been transplanted. The aim is to eventually move these organs in to the standard offering processes when 75% of recipients are consented to use these. | **Julie Whitney to confirm consent rates** |
| **6.5** | **Appeals process for small HCCs - LAG(23)13, LAG(23)13b - for noting** | |
| | D Thorburn confirmed that there will be a monthly MDT to discuss cases. The letter and proforma for cases will be sent to centres, there will be a prospective audit of patients with tumours that are two to five centimetres also, to investigate the decision to transplant. | |
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| **7.** | **LDLT Project** | |
| | L Burnapp provided a link to the NHSBT webpage that contains resources relating to the project;<br>https://www.odt.nhs.uk/living-donation/living-donor-liver-transplantation/<br>She confirmed that at the recent stakeholder meeting in February there was endorsement for two key recommendations; The operational model for rolling out an adult living donor liver transplant program and endorsement for updating some clinical pathways for the recipients of the organs.<br>It was agreed to develop a proctor team model to work with centres as they come online, to provide support and mentorship. She highlighted a recent proctor case on March 22nd between Leeds and Royal Free, with NHSBT completing a controlled risk assessment process.<br>There are 4 workstreams;<br>i. Operational model and workforce resilience and sustainability<br>ii. Indications for LDLT donor and recipient assessment and follow-up<br>iii. Educational Resources<br>iv. Commissioning<br>The adult recommendations will be embedded in joint BASL & BTS guidelines and the workstreams are also looking to endorse the paediatric programme. The educational workstream will look at developing donor resources.<br>A paper has been submitted to NHSE, asking for £300,000 over three years, to support the development of the proctor team. | |
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| **8.** | **Digital Infrastructure for Utilisation Project (EOS Replacement)** | |

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| | H Bullock presented the Prototype for TransplantPath which will be a web-based application with a single sign-on. She asked members for volunteers to be involved in testing and to consider what the impact will be on their centres. H Bullock provided her email address to the Group. | **All** |
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| **9.** | **RAG Update** | |
| **9.1** | **Paediatric offering pathway paper - LAG(23)14** | |
| | I Currie was not present at the meeting; J Whitney acknowledged and recognised his work and that of the FTWG that completed it. The key points are that in 2011, a lot of paediatric livers were perfused between 8am and midnight with the trend has moving to between midnight and 8am. Reperfusion times for right lobes are consistently over 12 hours, compared with between 8 and 9 hours for the left lobes.<br>The key recommendation is that at the time of acceptance of the split, the accepting centres should indicate what elements of the liver they intend to use. Once an offer is accepted, presuming there are no super-urgent recipients awaiting either liver graft, a plan should be made for NORS teams to arrive at the donor hospital between midnight and 3 am.<br>The Hub will identify the most appropriate rather than the geographically closest NORS team. The graft will be split at the most appropriate centre as previously grafts were travelling a long distance.<br>The group discussed implementing paediatric donor zones and the increase in the number of right lobes being discarded. T Perera advised that there are less than 100 split livers per year. Some are not split as the surgeon will assess the liver and the anatomy before the decision is made and are used as whole organs. Right lobe utilisation will be examined further. | |
| **9.2** | **NRP quarterly report - LAG(23)15 - for noting** | |
| | C Watson confirmed that the latest data on conversion rates is 63% from donor dying to the liver being transplanted. He confirmed that Oxford, Manchester and the Royal Free are not yet included from the donor side but Newcastle, Edinburgh, Cardiff and Birmingham are. | |
| **9.3** | **Super-urgent liver pathway paper - LAG(23)16 - for noting** | |
| | J Whitney confirmed that the timings have improved since the data was presented in this paper. NHSBT are working with the CT teams to try and improve the acceptance timings to reduce the pathway further. | |
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| **10.** | **Liver CLU Scheme and Liver Utilisation** | |
| **10.1** | **Offer review scheme** | |
| | R Prasad provided an update on the higher quality donor Offer review scheme, advising that in the last five months only one letter has gone out. He has handed this over to D Manas until a new Lead liver CLU is in post. This letter was regarding perception of a higher risk organ, not a fatty liver or abnormal LFT. | |
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| **11.** | **Governance Issues** | |
| **11.1** | **Non-compliance with allocation** | |
| | There was no non-compliance reported. | |
| **11.2** | **Governance report - LAG(23)17** | |
| | S Sinha confirmed that the UW solution situation is ongoing with centres moving to HTK. He highlighted that the NHSBT Governance team thank all centres for providing the information required to report on incidents, reiterating that all centres have a responsibility to the HTA to provide the information required to answer cases and close incidents. | |
| **11.3** | **CUSUM** | |
| **11.3.1** | **Summary of CUSUM monitoring of outcomes following liver transplantation - LAG(23)18**<br>There were no national triggers for CUSUM, only one centre specific CUSUM. | |
| **11.3.2** | **Report on recent triggers (shared learning)** | |
| | In the period since the last LAG meeting there are no relevant cases currently to report to LAG for discussion. | |
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| **12.** | **Statistics and Clinical Research Report** | |
| **12.1** | **Summary from Statistics and Clinical Research - LAG(23)19** | |
| | R Taylor advised that the Adult Risk Communication Tool will be updated shortly. | |

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| | An NHSBT Clinical Fellow will start in September looking at inequalities in access to liver transplantation.<br>Clarity has been added to the Liver Selection Policy regarding how patients who turn 17 while on the transplant list should be handled. | |
| **12.2** | **National Clinical Trials - LAG(23)20** | |
| | R Taylor provided an update on the clinical trials in organ donation and transplantation that are ran by the NHSBT Clinical Trials Unit (CTU). There are currently 8 current trials, with the DeFat Study opening to recruitment on 23rd February 2023, with two centres open. PLUS has now reached its recruitment target of 1035 livers across the 7 UK liver transplant centres and closed to recruitment ahead of schedule. | |
| **12.3** | **Follow-up form return rates in Annual report on liver transplantation - LAG(23)21** | |
| | Form return rates that will be reported in the Annual Activity Report were highlighted. | |
| **12.4** | **PROMS & PREMS in solid organ transplantation** | |
| | R Jenkins introduced herself to the group, advising that the broad scope of the research she is undertaking is to integrate patient reported outcome and experience measures with the UK Transplant Registry.<br>All members were encouraged to complete the online survey; https://odt.btru.nihr.ac.uk/measuring-patient-experiences-and-outcomes-in-solid-organ-transplantation-a-survey-of-current-practice/ | **All centres** |
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| **13.** | **Multi-visceral and Composite Tissue Advisory Group (MCTAG) update** | |
| | A Butler was not present at the meeting, P Gibbs provided an update of the problem of low numbers of donors for paediatric liver/ small bowel multivisceral transplants. A Butler is talking to a team in Spain who do DCD NRP multivisceral transplants who will be attending MCTAG next week. | |
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| **14.** | **AOB** | |
| | D Thorburn advised that T Grammatikopoulos currently chairs a Paediatric LT Group, which should be more formalised to feed into LAGCG as a Sub-Group. There were no objections from members to this proposal, this was agreed.<br>D Thorburn advised that a request was made to make summary points of LAG, for representatives to feedback to their centres. He asked if, on a rotational basis, a centre representative could provide this summary to share with the other centres .M Cramp will provide these for this meeting.<br>D Thorburn advised that the LAG Deputy Chair, J Isaac, is retiring on 31st July 2023 and offered his appreciation of his contribution. The process for appointing a new LAG Chair and Deputy Chair will be starting soon.<br>A Dillon advised that there has been an increase in Cholangiocarcinoma referrals to Dublin from UK centres.<br>Dublin data will be included in the benchmarking process and will be included in this years annual report on liver transplantation. | **M Cramp** |
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| **15.** | **Date of next meeting**<br>29 November 2023 - F2F -<br>Mary Ward House, 5 - 7 Tavistock Place, London, WC1H 9SN | |
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| **16.** | **FOR INFORMATION** | |
| **16.1** | Group 2 Transplants - **LAG(23)22** | |
| **16.2** | HCC Downstaging - **LAG(23)23** | |
| **16.3** | Outcome of appeals - **LAG(23)24** | |
| **16.4** | Prioritised paediatric patient outcomes - **LAG(23)25** | |
| **16.5** | Activity and organ utilisation monitoring (dashboard) - **LAG(23)26** | |
| **16.6** | Minutes of MCTAG meeting - **LAG(23)27** | |
| **16.7** | Minutes of the Retrieval Advisory Group - **LAG(23)28** | |
| **16.8** | QUOD Statistical Reports for LAG - **LAG(23)29** | |
| **16.9** | IT Changes and Update **- LAG(23)30** (Liver splitting criteria, FT trigger, Update of NLOS & Crossmatch) | |
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