NLOS Review: Joint Patient Response

Date: 14 April 2025

Executive Summary

The charities signed below (hereafter referred to as ‘we’) welcome the National Liver Offering Scheme (NLOS) 5-year review. We are encouraged that the patient and public voice has been actively sought out to contribute to this review.

As patient organisations and representatives we would like to add the weight of our collective voices to this discussion with this statement and patient testimonials.

Recommendations

We hope that by taking these recommendations into account, progress can be made toward ensuring more equitable access across all patient groups.

We recommend:

- **that the calculation of the NLOS algorithm is peer reviewed and shared in a transparent way to aid patient and public understanding**
- **that quality of life is included in the decision about who is offered the next most appropriate liver**
- **the recipient age weighting in the NLOS algorithm is reviewed**
- **further discussion about the use of donation after circulatory death livers and national versus regional offering**
- **the continuation of the NLOS monitoring committee (with patient and public involvement)**
- **the NLOS review committee publishes of the results of the patient and public consultation**

Transparency of NLOS Algorithm

We recommend that the NLOS Transplant Benefit Score (TBS) algorithm is peer reviewed and presented in a transparent way in order to instil patient and public confidence in NLOS and in organ donation. The calculation is a complex and somewhat abstract concept, and the weight given to the TBS variables is not clear[1]. Lack of transparency may lead to a loss of trust in the patient-doctor relationship and lead to the spread of misinformation about perceived disadvantaged populations. Greater transparency and effective communication would help patients understand the decision-making involved in their liver transplantation.

Quality of Life

We understand that the TBS is built on the foundational basis of pre- and post-transplant survival. We understand that this has resulted in fewer people dying while waiting for a liver transplant. While we appreciate that NLOS was not intended to equalise waiting times across specific groups of patients, it is clear that some groups are waiting much longer than others. For some, quality of life is so poor, they report that they are existing rather than living, with some even reporting suicidal ideation while on the list (see patient testimonials below).

We therefore recommend that quality of life while on the transplant list is incorporated as a variable into NLOS as a whole (and quality of life routinely monitored).

We appreciate that meaningful measurement of quality of life across patients with different aetiologies is challenging; nevertheless, it is essential that proactive efforts are made to address this complex issue.

Age Weighting

Due to the lack of longer term data when the scheme was initially set up, the TBS algorithm uses a five year follow-up to calculate how long someone will live after their transplant. This underestimates the benefit for younger people.

With more data now available, consideration should be given to placing greater emphasis on potential life years gained beyond the current five-year cap. In addition concerns have been raised about the weighting of age as a variable in the calculation:

“The UK liver allocation algorithm prioritises older patients for transplantation by predicting that advancing age increases benefit from liver transplantation. The predicted benefit of performing a liver transplantation in older patients, even below minimum UK listing criteria, exceeds that of many younger patients with high–urgent disease severity (UKELD score >60).” [2]

We recommend these concerns are addressed. By refining the algorithm, we can ensure a fair and effective allocation system for all patients on the waiting list.

Continuing Monitoring

We understand that as a result of ongoing monitoring, the NLOS algorithm was adjusted to seek to address an unintended consequence for hepatocellular carcinoma patients on the waiting list[3, 4.]. We would welcome an update on whether this change has had its intended effect.

We recommend that this important work from the NLOS monitoring committee continues to ensure that algorithm's adjustments can be made in a timely manner if and when required.

Use of DCD Livers

NLOS uses donation after brain stem death (DBD) livers in the TBS calculation and donation after circulatory death (DCD) livers are allocated by individual centres. We would like further discussion on the use of DCD livers for transplantation, including how this is affected by NLOS decisions.

Regional v. National Allocation

We understand that currently DBD livers are offered through NLOS on a national basis whereas DCD livers are still regionally allocated. We would welcome further discussion around this.

Patient Testimonials

Below are testimonials from people who have had liver transplants, which highlight the importance of quality of life:

"I waited over 3 years for a liver transplant. By the second year of waiting I had got so ill I couldn't work. I couldn't do anything but nap on the sofa. No job. No social life. No energy for hobbies. No income. No government benefits. I wasn't living; I was existing. Getting a liver was great but I had to start from 0 in my career and am left with this pervasive feeling of having to 'catch-up' or 'give back' that causes me to take on too much and burn out further harming my future health."

Patient, aged 39 at transplant

"Going on the list itself is a huge thing to take on, when's the call going to come? Praying for it to come as you get worse by the week. The cholangitis attacks were at least twice in a week. I was calling the liver coordinators in Edinburgh, my consultant in Glasgow desperate for someone to help me & take this all away. At this point I pretty much had to stop work. I felt angry. Why at 40/41 was I having to go through this? I could barely walk any distance in the late months. I was angry: my amazing busy life had hit a brick wall and I couldn't look after myself."

Patient, aged 41 at transplant

"It is a secret that I never told anyone but after a couple of years on the waiting list I had come up with a plan on how I could end it all on my own terms if my life got any worse. Life just wasn't worth living."

Patient, aged 27 at transplant

"My symptoms from my PBC made any type of normal life impossible. My intractable itch meant that sleep was almost impossible, as was doing anything really. The itch was just present 24/7 to the point that it took over my life. It made me fear that I would end up being sectioned before I received a transplant as I simply couldn't function due to not sleeping. I couldn't hold down a job, or even do basic tasks in the home. It was good day if I simply managed to get up and showered and dressed.

Which was a huge burden to carry. I knew that as I was listed due my itch I was on the variant syndrome list, which inevitably meant a longer wait, and with my blood group being B- this compounded the wait. I was however very fortunate to receive my transplant two years to the day of my assessment and it has been life changing, in the last 15.5 months I've only returned to hospital for check ups, and am able to lead a normal life again."

Patient, aged 46 at transplant

We remain committed to supporting equitable and transparent practices in liver transplantation and the continued work with stakeholders to improve the system for everyone. We welcome opportunities to work together to ensure that the needs of patients can be best met. We thank you for canvassing patient views on this important issue, and look forward to hearing the outcome of this review.

Signatories

Patient Organisations:

(alphabetical order)

- Addenbrooke's Liver Transplant Association
- AIH Support
- LIVErNORTH
- PBC Foundation
- PDK Charity
- PSC Support
- Royal Victoria Hospital Liver Support Group

Patient and Public Signatories

This response was made available to patients and the public to sign from 14 April to 21 April. In the week it was live it garnered **103 signatories** (74 named, 29 anonymous). An addendum with names will be supplied separately due to data protection responsibilities.

References

1 Berry P, Kotha S. Communicating the complexity of the transplant benefit score. Journal of Hepatology. 2025 Mar 1;82(3):e153-4.

2 Attia A, Webb J, Connor K, Johnston CJ, Williams M, Gordon-Walker T, Rowe IA, Harrison EM, Stutchfield BM. Effect of recipient age on prioritisation for liver transplantation in the UK: a population-based modelling study. *The Lancet* Healthy Longevity. 2024 May 1;5(5):e346-55.

3 Stutchfield BM, Attia A, Rowe IA, Harrison EM, Gordon-Walker T. UK liver transplantation allocation algorithm: transplant benefit score–Authors' reply. The Lancet. 2023 Jul 29;402(10399):371-2.

4 Attia A, Rowe IA, Harrison EM, Gordon-Walker T, Stutchfield BM. Implausible algorithm output in UK liver transplantation allocation scheme: importance of transparency. The Lancet. 2023 Mar 18;401(10380):911-2.