

**NHS BLOOD AND TRANSPLANT
LIVER ADVISORY GROUP**

Options for low UKELD variant syndromes**Background**

Some patients may be disadvantaged by the current and proposed system. This is because UKELD score underestimates their risk of dying on the list (or of being removed from it) or because their risk of dying is low and they are being considered for transplant to improve their quality of life. Some belong to the current “variant syndromes”. Some have chronic liver disease for which the UKELD system is appropriate but require additional points to restore equity. Some receive a transplant to treat non-liver disease, for which the UKELD score is irrelevant.

The following groups are felt to be disadvantaged:

- 1. Hepatopulmonary Syndrome (HPS)**
- 2. Portopulmonary Hypertension (PPH)** (I am not sure this should be an indication anymore, for further discussion!)
- 3. Polycystic Liver Disease (PCLD)**
- 4. Familial hypercholesterolaemia**
- 5. Porphyria**
- 6. Glycogen storage disease**
- 7. Primary Hyperoxaluria**
- 8. Hepatic Epithelioid Haemangi endothelioma (HEHE)**
- 9. Intractable pruritus**
- 10. Cholangiopathy with refractory cholangitis or intrahepatic sepsis**

Potential options for these patients

1. Proportional allocation
2. Points based adjustments to proposed scheme
3. No exemption system

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1. Proportional allocation

In this system the percentage of registrants with low UKELD variant syndromes (LUVS) would be matched on a yearly basis with a percentage allocation from the donor pool. For example if 5% of patients were registered within this category every 20th donor would be offered to a LUVS patient. Patients would need to meet national criteria for listing and would be ranked on time spent on the list given the inability to prioritise in any other meaningful way.

Advantages

- Simple
- System is not prone to points inflation (recent data from the States demonstrates this risk *Northup et al Hepatology 2015;61:285-291*)
- It can adapt to demand (both increase and decrease)
- Provides a response mechanism to address negative unintended consequences in main offering scheme
- Provides a mechanism for innovation

Disadvantages

- It may encourage early listing of variant syndromes
- No system for ranking dependent on predicted mortality
- There may be requests for other diseases to enter into this system. A different method of inflation
- It might increase the chance of death for high UKELD patients and HCC patients on the national list

2. Points based system

Advantages

- Maintains transparency of offering system

Disadvantages

- Artificial system that may not reflect non-mortality related benefit
- Separate systems will be needed for each indication
- Restricts innovation

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3. Utilise proposed national offering system with no exemptions for low UKELD variant syndromes

Advantages

- Simple
- System is not prone to points inflation (recent data from the States demonstrates this risk Northup et al Hepatology 2015;61:285-291)

Disadvantages

- Risk of death will always over-ride other benefits
- Likelihood of receiving a transplant low