KAG

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Prioritisation options of paediatric kidney patients

1. Executive Summary

Due to the impact of COVID-19 there have been significant increases in paediatric patients awaiting a kidney transplant in the UK from 73 (on 31/03/15) to 119 (on 31/03/24). This has had a direct impact on paediatric units due to restricted dialysis capacity. One possible mitigation is considering temporary changes to the kidney offering scheme aimed at increasing paediatric kidney transplantation activity, whilst the long-term solution of improved organ offer acceptance is pursued.

This paper covers the background to the impacts on paediatric dialysis units and the suggested solutions and associated risks.
A more detailed analyses of paediatric kidney transplant organ offers, offer acceptance, and transplant activity is described in Appendix 1 (paper titled – KAG PSG annual review of 2019 KOS).

2. Action Requested

KAG & KAG-PSG voting members are requested to consider and vote on the options.

3. Background

3.1 Kidney Offering Schemes prior to 2019 had established paediatric prioritisation (kidneys offered to paediatric patients prior to offer to adults). The 2019 KOS removed age dependant prioritisation and was replaced with prioritisation of highest quality donors matched to healthiest recipients (D1 kidneys to R1 recipients and so on). The 2019 KOS also had additional priority for waiting time and HLA sensitisation, changes designed to help the longest waiting/hardest to match patients of all ages on the WL. The simulation modelling for the 2019 KOS highlighted that paediatric transplant activity would see a temporary drop-in activity for 6-12 months (to account for increased offers to long waiters) after introduction with subsequent return of offer numbers to previous baseline, with a much higher proportion of offers from highest quality donors (D1 or D2).

3.2 After accounting for the impact of the pandemic in 2020/2021, recent review of the 2019 KOS (see Appendix 1) confirms the accuracy of simulation models, with paediatric offer numbers reducing in the first year followed by recovery to baseline (Fig 1.1: SPC chart of offers per 100 donors of eligible donors), quality of organ offers improved (Table 1.2: Quality of offers – number of donors by donor risk index group) despite which offer declines remained at

approximately 50% with DCD turn downs being even higher (Table 1.1: centre specific kidney offers for named patients).

3.3 The introduction of the 2019 KOS with its' predicted decline in paediatric offers in the first 6-12 months and the pandemic associated reduction in transplant activity in 2020 & 2021 effectively created a 'back log' of un-met demand resulting in the paediatric waiting list, which had remained stable at ~90 patients for many years, increasing to 120 by 2024.

3.4 Unlike adult dialysis services where majority of the dialysis activity is provided at off-site or satellite dialysis units closer to patient homes, paediatric dialysis capacity is usually in-centre and is only available in a small number of tertiary paediatric centres, often many miles from patient homes. Most paediatric dialysis services have very limited resilience and despite efforts cannot bring additional capacity on-line within required timelines. These factors have meant, the increase in paediatric waiting list from 90 to 120, has had a disproportionate impact on this specific patient population.

3.5 Paediatric live donor kidney transplant activity which had declined between 2020-2022 has now returned to pre-pandemic levels and as such is not contributing to the problem of limited dialysis capacity.

3.6 An increase in paediatric deceased donor transplantation activity would mitigate the dialysis capacity constraints and could be achieved by a combination of (1) improved organ offer acceptance by paediatric clinicians. For example, a 10% increase in organ acceptance (from 48% to 58% as per Table 1.1 in Appendix 1) would result in an additional 10 transplants/year (2) revise (by changing the number of points for paediatric patients) the 2019 KOS to offer paediatric prioritisation.

3.7 KAG-PSG is already working with clinicians from all paediatric kidney transplant centres to review organ turn-downs and change clinician behaviour, especially for DCD offers. Whilst there is active participation in this project, it is recognised challenging un-warranted variation in risk appetite in a supportive way to enable a change to clinical culture/behaviour will require time to embed. Whilst this change is being enacted as the long-term solution to reduce and maintain the paediatric waiting list at a level commensurate with available dialysis capacity, the rest of this paper sets out time limited options with their relative risks/benefits with options that could increase paediatric transplant activity.

4. Option to revise 2019 KOS to enable additional paediatric activity

4.1 KOS 2019 already offers prioritisation for better HLA match for younger patients (HLA*Age) as this is clinically necessary. HLA level 1 match is best matched with Level 4 being the least well-matched offer. For e.g. current scheme affords a minimum of 1200 and maximum of 3500 points for Level 1 mis-match for younger patients (Fig 1). Based on current points, approximately 95-97

paediatric transplants are predicted over 2 years. One option for KAG/KAG-PSG to consider is a revision of this points system.

4.2 A series of simulations were undertaken to explore additional points on the HLA* Age system and its' predicted impact on additional paediatric transplant activity versus impact on adults on WL (including opportunity for difficult to match patients, highly sensitised, and ethnicity impact). After a series of such simulations, if HLA*Age was updated as per simulation 2 as per Fig 2, (minimum points 1500, maximum 4100 for Level 1 mis-matches) then it is simulated that 113 paediatric transplants would be undertaken, an additional 17 transplants over 2-years on the current scheme.

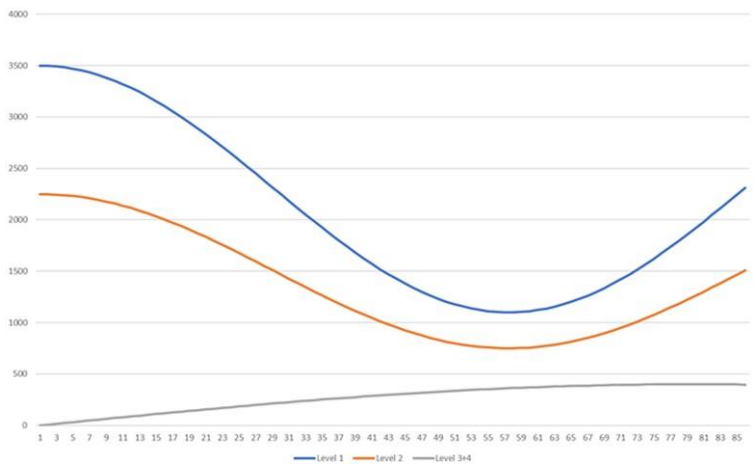

Fig 1: Current HLA*Age scheme

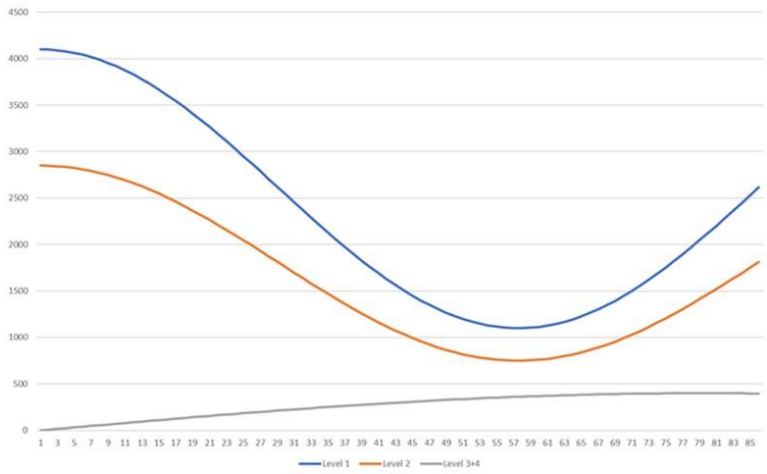

Fig 2: Proposed change to HLA*Age scheme

4.3 In Simulation 2 we would see no difference in difficult to match or highly sensitised patients being transplanted, with a reduction in waiting time for paediatric patients from 251 days to 128 days but slight increases to waiting time for patients aged 50-69 from 560 days to 600 days. The modelling does not identify any detrimental impact due to ethnicity in the paediatric or adult populations.

5. Options and associated benefits/risks:

As described above, KAG-PSG has already commenced work to improve organ offer acceptance and reduce un-warranted variation in risk appetite for offer acceptance as well as increase organ offer acceptance from DCD donors as UK donor demographic has changed to majority DCD donors. It is expected this supported education and culture change process will take 1-2 years to embed and then remain as the long-term solution.

For all options below, the suggestion is, if any change is introduced, it is time-limited for 2 years at the end of which a review is undertaken by KAG before recommending whether any changes are discontinued or continued further.

Option	Associated risk	Associated benefit	Work involved
(1) Do Nothing	Negative impact on paediatric patients due to limited dialysis capacity remains unchanged	No impact for adult patients on WL	No additional work required
(2) Alter HLA*age points in kidney offering scheme to give more prioritisation to paediatric patients for a fixed term of 18-24 months (no extension beyond 24 months without OTDT SMT involvement).	Adult patients will wait longer for transplant. Requires update to REF table on Transplant Registry	Younger patients already receive higher points for better HLA match due to clinical reasons and will be transparent.	Update to REF table in the National Transplant Registry with associated testing.

6. Recommendation

Option 2 (as per simulation 2) is recommended as the preferred option to minimise risk to the paediatric patient population in the short-term (minimum 18 months, maximum 24 months).

If KAG approves Option 2 (as per simulation 2), then an interim review at 9 months and definitive review at 18 months, is mandated to review outcomes (and any unintended consequences). During both interim and definitive review, KAG-PSG chair will have responsibility of reporting on improvements in paediatric organ offer acceptance and KAG chair will have responsibility on reporting on impact to adult patients.

The results of the definitive review will need to be shared with OTDT SMT

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Appendix 1:

APPENDIX

Appendix Table 1 - HLA mismatch levels for HLA-A, B and DR

Level	HLA mismatch summary	HLA mismatch combinations included
1	000	000
2	[0 DR and 0/1 B] or [1 DR and 0 B]	100, 010, 110, 200, 210, 001, 101, 201
3	[0 DR and 2 B] or [1 DR and 1 B]	020, 120, 220, 011, 111, 211
4	[1 DR and 2 B] or [2 DR]	021, 121, 221, 002, 102, 202, 012, 112, 212, 022, 122, 222