

## **Proposal to expand KAG to include clinical representation from non-transplanting kidney units, trainees and patient representatives**

### **Introduction:**

Current membership of KAG has one clinical representative for twinned kidney transplant centres in Eng/Scot/Wales + a representative from NI. Thus all 23 kidney transplant centres in the UK are represented with members taking turns between the twinned transplant centres with a maximum tenure of 4years. In the UK, >65% of ESRD patients are cared for in non-transplanting renal unit (49 in total). Thus 2/3 of all patients will start their renal replacement therapy (RRT) pathway in a non-transplanting renal unit. These non-transplanting units are paired with one or more geographically aligned transplanting units for the purposes of enabling transplantation for the patients under their care. Both referral into and repatriation post transplantation practice varies between the different transplant – non transplant unit networks. The pathway needs for patients commencing their RRT journey in a non-transplanting unit are subtly different to counterparts in a transplanting unit with diminished access to pre-emptive listing/transplantation as well as LKD transplants. Current KAG clinical membership is not able to accurately and first-hand reflect the needs and/or provide advocacy for this patient population to ensure policy decisions meet such needs.

Current trainees in transplant surgery and transplant nephrology will be responsible for meeting the challenges and designing & implementing the innovations in kidney transplantation in the next 5-10 years. Early exposure to national clinical leadership and policy development forums will help cultivate the leaders of the future as well as hear their voice during policy development to ensure the needs of the future workforce informs decision making.

Involvement of patient representatives in Advisory Groups (LAG, PAG) has been shown to result in critical sense check of discussions to ensure the patient need is at the centre of decision making. Inclusion of patient representation would help guide the Advisory Group from a user perspective as well as ensuring the patient voice is clearly heard.

Prior to the pandemic, KAG meetings were held exclusively face-to-face and required travel to a central location. In the post-pandemic world it is likely the majority of meetings will be virtual or hybrid (allowing participation either F2F or virtual dependant in individual preference). In this setting, it is unlikely that any additional travel reimbursement costs for the expanded membership will be prohibitive given overall reduction in costs.

### **Proposal:**

It is proposed the clinical membership of KAG is expanded to include:

(1) Two consultant nephrologists from non-transplanting renal centres. Nominations for these 2 positions should be sought from the Renal Association UK (Society of DGH Nephrologists sub-group). It is expected that these colleagues will be voting members of KAG and have tenure of 3 years .

(2) Transplant surgical trainee representative nominated by the Herrick Society (sub-group of BTS). It is expected that the trainee will be ST5+, has demonstrated clinical/academic interest in kidney transplantation and the tenure will be for 2 years.

(3) Transplant Nephrologist trainee representative nominated by the SpR club (sub-group of RA). It is expected that the trainee will be ST5+, has demonstrated clinical/academic interest in kidney transplantation and the tenure will be for 2 years.

The trainee reps will be non-voting members of KAG.

(4) Two patient representatives with one nomination from Kidney Patient Group and one from NHSBT Patient committee to be non-voting members on KAG with a tenure of 3 years.

To ensure that costs associated with reimbursement for travel expenses are within the allocated budget, (a) OTDT will enable the option of virtual attendance at bi-annual KAG meetings (b) non-voting members will be encouraged to attend the meeting virtually. Only patient representatives who want to attend the meeting in person will have their costs reimbursed.

**Recommendation:**

The voting members of KAG are asked to indicate support (or objection) to the following recommendations to expand KAG membership

- (1) by inclusion of two non-transplant unit Nephrologists
- (2) by inclusion of trainee representatives
- (3) by inclusion of patient representatives

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