Human Tissue Authority

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Dear Living Donor Coordinator,

**Living donation update**

It was good to see so many of you at the network meeting in May. We recognise that there are a lot of demands on everyone’s time at the moment and we would like to thank you for commitment in making things work.

There is increased risk posed by the growing threat of human trafficking for the purpose of organ removal and we all need to be alert to this. It’s crucial that we continue to ensure robust processes are in place.

By the end of 2023 we will publish revised Guidance to transplant teams and Independent Assessors. Current guidance can be found [here](https://www.hta.gov.uk/guidance-professionals/regulated-sectors/organ-donation-and-transplantation/living-organ-donation-1). Our Code of Practice on living donation also contains essential information and can be accessed [here](https://www.hta.gov.uk/guidance-professionals/codes-practice-standards-and-legislation/codes-practice) (not applicable in Scotland).

By April 2024, all Independent Assessors will be asked to attend mandatory targeted refresher training, which will include information on signs and indicators of trafficking. Sumrah and I will also be joining the LDC Ops call on 27 July to help address any uncertainties and answer any questions you may have.

There has been a change in the nature of the cases we are receiving for approval, many cases are more complex. There has been an increase in directed cases where the relationship between donor and recipient is remote. Many of these are being submitted without evidence to demonstrate the claimed relationship.

We know you are working to tight timelines and delays and clarifications cause frustration. It may take longer for the HTA to make a decision on some cases. Please be reminded that it is a criminal offence under the Human Tissue Act 2004 for a living donor transplant to proceed without HTA approval.

With your help, we can keep delays to a minimum. One of the key things you can do is ensure donors and recipients arrive at the Independent Assessor interviews prepared, with the evidence needed to substantiate their claimed relationship. The following may be a useful reminder:

* **Donors and recipients need to bring correct ID and evidence of their claimed relationship to the IA interviews.** **Please ensure donors and recipients know what to bring with them.** 
  + We receive a significant number of cases where patients arrive at IA interview without any, or insufficient evidence to demonstrate the claimed relationship. This causes delay in our ability to make timely decisions. In line with [Guidance](https://www.hta.gov.uk/guidance-professionals/regulated-sectors/organ-donation-and-transplantation/living-organ-donation-1), evidence could be marriage certificates, birth certificates etc. If photographs are shown, all parties should be identifiable in photographs spanning the length of time of the relationship.
* **Please ensure all donors are provided with a copy, or a link, to the HTA** [Guidance](https://www.hta.gov.uk/guidance-public/body-organ-and-tissue-donation/living-organ-donation/independent-assessment-process) on the independent assessment process.
* **Please allow plenty of time for referral of cases requiring a decision by an HTA panel.** 
  + As a reminder all non-directed altruistic, paired and pooled cases are referred to panel. Some directed altruistic cases are also referred. We must receive the case from the IA by 9am on a Monday to refer to a panel that week.
  + Referrals to panel take place every Wednesday and the panel has 10 working days to make a decision. Most panel members have full time day jobs and need appropriate time to make a considered decision (for robust decision making) as they each receive several cases a week for decision.
  + Requests for very short turnaround times are increasing and are becoming difficult to accommodate. We appreciate the pressures and ask you to review your referral timeframes and ensure cases requiring decision by a panel are referred to the IA as early as possible. You need to allow 3 to 4 weeks for a HTA decision in these cases.
  + Please remember you can refer donor and recipient pairs that have been registered, but not necessarily matched,in the National Kidney Sharing scheme, for IA and HTA decision.  This does not apply to recipients registered with more than one potential donor.
* **Interviews by the IA need to be conducted with the donor alone, the recipient alone and both together (in any order).**
  + Third parties including other family members should not be attending interviews unless there is a specific need to do so. Please contact the HTA in advance for advice and ensure donors and recipients are clear on expectations.
* **All supporting documents, referral letters and donor declarations must be uploaded by the IA at the same time as their report.** We are unable to receive these by email.
* **Where a surgery date is scheduled, please ensure the IA is aware so it can be included in their report to the HTA.**

Once again, we appreciate the time and effort that goes into this work, and we thank you for your continued support and collaboration. Please contact us on [transplants@hta.gov.uk](mailto:transplants@hta.gov.uk) if we can offer any further advice or guidance.

Yours sincerely,

Jess

Jessica Porter

**Head of Regulation**

**Organ Donation and Transplantation**