

## Minutes of Transplantation Advisory Group

---

**Date** 14 October 2016

**Venue** Board rooms 1 & 2, Human Tissue Authority  
151 Buckingham Palace Road  
London  
SW1W 9SZ

**Protective Marking** OFFICIAL

---

### Present

#### Members

Allan Marriott-Smith (AMS) (Chair), CEO

Sam Abdalla (SA), Authority Member

Lisa Burnapp (LB), Lead Nurse for Living Donation, NHS Blood and Transplant

Amanda Gibbon (AG), Authority Member

Keith Rigg (KR), Consultant Transplant Surgeon, Nottingham

Lorna Williamson (LW), Authority Member

Anthony Warrens (AW), Authority Member

Michael Heneghan (MH), Consultant Hepatologist, Kings College Hospital

Penney Lewis (PL), Authority Member

Jessica Porter (JP), Head of Regulation (Organ Donation and Transplantation Sector)

Chitvan Amin (CA), Transplant Manager

Niamh Marren (NM) (Secretary), Living Donation Officer

Amani Robinson (AR), Living Donation Officer

#### Apologies

Sharmila Nebhrajani (SN), Authority Member

Sarah Bedwell (SB), Director of Regulation

### **Item 1 – Welcome, apologies and minutes from 22 April 2016 Meeting**

1. Apologies were received from SN and SB.
2. The minutes from the 22 April 2016 meeting were agreed.

### **Item 2 – General Update**

3. JP outlined that consideration will be given to widening the membership of the TAG, and whether it would be appropriate to have an Independent Assessor (IA) representative and / or a professional working in the deceased organ donation sector. It was acknowledged by the group that this would only be appropriate where agenda items were relevant, as they are often living donation focussed.

#### **Action**

1. **To consider wider group membership.**

### **Item 3 – LDAR 2015-15 Q4 and LDAR 2016-17 Q1**

4. CA updated the group on the LDAR 2015-16 Q4 report and the LDAR 2016-17 Q1 report.
5. The group suggested that where graphs were included it would be helpful, in addition to the percentages which are currently provided, to have total number of variables shown on the graphs.

### **Item 4 – Update on outstanding actions from previous two TAG meetings**

7. JP updated the Group on the outstanding actions from the previous two TAG meetings.
8. Legal advice had been sought for some outstanding actions and was discussed in detail under item 5.
9. The group was informed that the Living Donation Assessment Team (LDAT) maintains a log of delays in IA report submissions. Where there is a delay, the IA is asked about the reason for delay and a reminder email is sent to inform them that an IA report should be submitted within 10 working days of IA interview.
10. The Group were informed that all other actions have been completed.

### **Item 5 – Updates on:**

#### **DBS and internal audit recommendations**

11. JP provided an update on the progress of the internal audit recommendations from August 2015. JP also informed the group that a follow up audit was due to take place on 20 October 2016 to review the progress on some of the recommendations made.
12. The main recommendation, in the internal audit report, was to ensure that all IAs have a valid enhanced Disclosure and Barring Service (DBS) (or equivalent) check in place. The LDAT has completed this challenging piece of work. All IAs but one have valid checks in place and these have been recorded on the HTA database.
13. The remaining IA and the relevant Living Donor Coordinator (LDC) have been informed that the IA must be chaperoned for each IA assessment until an up to date enhanced DBS certificate is provided to the HTA.
14. The HTA will, in future, apply for enhanced DBS checks for all newly accredited IAs.

#### **Action**

- 3. LDAT to continue to follow up the remaining IA about their enhanced DBS check and apply for enhanced DBS checks for all newly accredited IAs.**

#### **IA conference agenda**

15. The Group discussed the IA conference agenda for 22 November 2016 and made some suggestions for improvements. JP informed the group that all external speakers have confirmed their attendance.
16. The Group discussed the possibility of facilitating future IA conferences and/or IA training on Saturdays to improve attendance for similar events.

#### **Action**

- 4. LDAT to consider in future whether IA Conferences and / or IA training could be held on a Saturday to gain maximum attendance.**

#### **Legal advice 1**

17. The Group discussed the advice provided on the inclusion of donor specific risks in the statutory referral letter sent from transplant units.
18. It was agreed that it is the Clinician's responsibility to ensure risks have been discussed with the donor.

19. Under the Human Tissue Act 2004, the HTA has the responsibility to ensure each donor has given valid consent for organ donation. The donor should be provided with the information regarding both generic and individual, specific risks based on their health and lifestyle.
20. The Group had a discussion on amending the template referral letter to ensure the HTA can be assured that donor specific risks are considered and addressed with every donor where appropriate.
21. LB agreed that the structure of the template referral letter could be adapted to include donor specific risks. The current BTS guidelines on living kidney donor transplantation are under review and due to be published shortly. They will include more detail for clinicians about individual patient risks and risk scoring.
22. The Group felt that it would be unreasonable and disproportionate to provide a prescriptive list of risks. The suggestion was that blank text box or space could be provided in the referral letters to enable transplant units to record this information and tailor it to individual donors.

#### **Action**

- 5. The LDAT will review the current referral letter and discuss with the full Authority for decision.**
- 6. After a decision has been made by the Authority, JP will liaise with LB to communicate this change with wider transplant community.**

#### **Legal advice 2**

23. The Group discussed the advice on placing a time limit on an HTA living organ donation approval for donations within the paired/pooled scheme. JP informed the group that this advice was requested to inform planned policy changes in the timing of referral of paired / pooled cases.
24. The Group highlighted that placing a time limit on an approval was not practical. Alternatively, the HTA could consider mandating transplant units to inform the HTA when a donor and / or recipient's circumstances have changed. The LDAT would then liaise with the clinical team to decide next steps.
25. Several examples were discussed to define the circumstances which would lead to the HTA being informed by the LDCs or Clinicians e.g. life changing event.

#### **Action**

- 7. To update the 'Guidance to transplant teams and independent assessors' (IA guidance) stating that the LDCs must inform the HTA of**

**any change in circumstances to the donor / recipient pair. The guidance should also include some examples of cases when this may occur.**

### **Update on revision to the IA guidance document**

26. The group discussed the paper on the changes made to the IA guidance. It was agreed that the reviewed IA guidance will be shared with LB and KR before being published.

### **Action**

**8. LDAT to send the updated IA guidance to LB and KR to review and provide feedback.**

### **Expanding pool of IAs**

27. JP updated the Group about proposed actions to expand the pool of IAs. This is an ongoing piece of work.

28. The IA role specification has been reviewed and the living organ donation web pages (public and professional) are in the process of being updated. Once this has been completed, the LDAT will explore the existing communication channels to publicise the requirement of IAs at individual transplant units.

29. A more detailed piece of work is also planned for the next business year which will look at the wider sustainability of the IA framework. This would be helpful in addressing concerns about the IA system for example relying heavily on the goodwill of voluntary individuals to undertake a statutory role.

### **Action**

**9. The LDAT to update the public and professional webpages on the HTA website.**

**10. The LDAT to explore use of various communications channels to publicise information about the IA role and requirement of IAs at transplant units, for example, via public group forums and professional societies.**

### **Item 6 – Enhanced IA policy change and plan for implementation**

30. CA updated the Group on the planned policy change to remove the requirement to have enhanced IAs. This policy change was discussed at the April 2016 TAG meeting and approved at the Authority meeting in July 2016.

31. The policy change will be implemented in several stages by providing additional training to current IAs. The additional training will be provided primarily via a number of webinars next year.

32. It was suggested that the LDAT should think carefully about the planning and dates / timings of the webinars to ensure maximum uptake.

#### **Action**

**11. The LDAT to consider webinar attendance for training and plan for maximum uptake.**

**12. The LDAT to prepare the content of refresher training**

**13. The LDAT to ensure refresher training is provided to all IAs before the policy change is implemented.**

#### **Item 7 – Summary of IA Survey – analysis and HTA actions**

29. NM presented a summary of the IA survey and the actions identified from the IA responses.

#### **Action**

**14. LDAT to circulate the IA survey report 2016 to all IAs and HTA stakeholders in the IA bulletin and at the IA Conference.**

**15. LDAT to complete the IA Survey actions.**

#### **Item 8 – Emerging trends and risks in living organ donation**

30. NM presented the paper on the trends and risks in the living organ donation sector. It was concluded that on the basis of the types of cases received by the HTA every year, it was difficult to identify any particular trends and/or risks.

31. The Group discussed whether the HTA is informed by the transplant units of cases that do not proceed due to evidence of duress, coercion or reward or organ trafficking and therefore are not referred to the HTA. JP informed the Group that this was not currently happening.

#### **Action**

**16. To discuss with the full Authority a piece of work or research on the presence of duress, coercion, reward and how that might fit with the priorities for the next business year.**

#### **Item 9 – AOB and date of next meeting**

32. The Group discussed whether the organ donation changes in Wales should be included as an agenda item at future TAG meetings. AMS informed the group that it is too early to determine any trends but will keep the Group informed of any updates.
33. LB informed the group that there is new information on the NHSBT website for liver and kidney donation, this includes interactive PDFs and leaflets.
34. The Group was informed that the NHSBT ODT congress in Warwick in September had been a success. Both CA and LB presented at the event and AG chaired the living donation session. It had included a session on living organ donation for the first time and the session had been well attended by people working in the living donor sector.
35. KR requested further information on the next round of on-site Organ Donation and Transplantation (ODT) sector audits. JP informed the group that these audits will begin week commencing 17 October 2016 and each establishment will receive three months advanced notice before their audit.
36. The Group was updated about the forthcoming IA reaccreditation. IAs that failed this process would be considered by TAG members.

## **Action**

### **17. LDAT to provide details of IAs who have not passed reaccreditation at the March TAG meeting for members to review.**

37. The Group was informed that Nima Sharma, Regulation Manager will be covering the role of Transplant Manager role, while CA is on maternity leave.
38. The date of the next TAG meetings will be held on 10 March 2017 and 18 October 2017.