Minutes of Transplantation Working Group

Date	26 February 2013
Venue	Boardrooms 1 and 2 Human Tissue Authority 151 Buckingham Palace Road Victoria SW1W 9SZ
Protective Marking	NONE

Present

Members	**In attendance**
Allan Marriott-Smith (Chair), Director of Strategy and Quality	Pravat Bhattacharyya, Regulation Manager
Victoria Marshment, Head of Performance	
Stacey Pengelly, Quality and Policy Manager	
Keith Rigg, Authority Member	
Catharine Seddon, Authority Member	
Rosie Glazebrook, Authority Member	
Michael Heneghan, Consultant Hepatologist, Kings College Hospital, London	
Lisa Burnapp, Lead Nurse, Living Organ Donation, NHSBT	
Diana Warwick, Authority Chair	
Alan Clamp, Chief Executive Officer	
Shaun Griffin, Director of Communication	
Katy Tinker (Secretary), Transplant Officer	

Item 1 – Welcome and apologies

1. Apologies were received from Gurch Randhawa, Sue Falvey, and Sarah Bedwell.

2. A welcome was extended to Pravat Bhattacharyya, Regulation Manager attending on behalf of Sarah Bedwell, and to Katy Tinker, Transplant Officer attending her first Transplantation Working Group Meeting.

Item 2 – Minutes from 12 September 2012 Meeting

3. The minutes from the 12 September 2012 meeting were agreed.

4. Action 2 – Keith Rigg took the issue of IA remuneration to the Department of Health working group that is drawing up a national tariff for kidney transplantation. Keith assured the Group that Independent Assessors (IAs) are included in the transplant workup process and will feed back when further information is received.

5. Action 5 – Lisa Burnapp has drafted guidance on behalf of the British Transplantation Society (BTS) on directed altruistic donation following on from the BTS Living Donor Forum and the BTS Ethics Symposium. The draft guidance will go out to consultation and be amended after all comments have been made.

Item 3 – Chair's update

6. Allan Marriott-Smith updated the Group on important activity that had taken place since the last TWG meeting in September 2012.

7. It was decided that in future Transplantation Working Group meetings the Living Donation Activity Report will be used as the Chair's update.

8. Allan Marriott-Smith noted that an IA training day took place in London on 31 October 2012. Six new IAs were accredited; three were from Scotland. It was the first training session delivered in the revised format of providing both theory and practical sessions, which allowed participants to explore how an independent assessment can be approached. This was the first time an established IA had spoken to participants on their experience as an IA.

9. A training day for new IAs had been scheduled to take place on 2 May in London. Transplant Units at Addenbrookes, St Heliers and Leeds have declared interest in participating.

10. Allan Marriott-Smith updated the Group on the IA reaccreditation. Out of 140 IAs, 122 have been reaccredited, 15 have been sent the refresher package and 3 have decided to step down from the role. Those who have stepped

down did so due to low living donation activity at their Transplant Unit. This year the reaccreditation process was revised slightly. Previously all IAs were provided a performance summary with a personalised letter to inform them of their accreditation status. This year efficiency savings were made by advising IAs they were reaccredited via a generic letter emailed to all IAs. IAs were informed that a summary of their performance would be available on request. Of those IA's who had passed, less than 10 requested their personal breakdown.

11. Allan Marriott-Smith updated the Group on the living donor statistics for Quarter 2 and 3. Combined there were 616 cases approved; 528 of which were approved by the Living Donation Assessment Team and 89 approved by Authority panels.

12. It was noted by the Group that the number of altruistic donations had risen and it was forecast that it would continue to rise as all Transplant Units were now facilitating this form of living donation.

13. Allan Marriott-Smith advised the Group on of the BTS conferences that were attended by HTA staff since the last TWG meeting. Allan Marriott-Smith presented at the BTS Living Donor Forum in November 2012 and spoke about the HTA Living Organ Donation Framework.

14. The HTA has had an abstract accepted at the Ethical, Legal, Psycho Social Aspects of Organ Transplantation (ELPAT) taking place in Rotterdam in April 2013. The abstract is on 'the regulation of living organ donation in the UK; progress since 2006 and meeting the challenge of social media'.

15. The Group was informed that Pamela Sandler was leaving the Strategy and Quality Directorate and her last day would be 5 April 2013.

Item 4 - Terms of Reference for Transplantation Working Group

16. The Group were asked to agree the terms of reference.

17. It was agreed that the Transplantation Working Group's name should be changed to Transplantation Advisory Group.

18. The Group agreed that the membership should be extended to four Authority Members and include a clearer definition on who could act as a clinical representative.

Action

1. **Executive to update the Terms of Reference to include four Authority Members and add a clear definition of clinical**

representative for the newly named Transplantation Advisory Group.

Item 5 - Independent Assessor reaccreditation

19. Views of the Group were sought on IA performance. The Group agreed with option 1 of the paper.

Action

2. **Executive to progress with option one with further discussion with Allan Marriott-Smith and relevant contacts.**

Item 6 – National Kidney Sharing Scheme (NKSS) cases and independent assessments.

20. Stacey Pengelly presented the paper for discussion. Stacey Pengelly gave a background of the issues in the paper and asked for the views of the Group on how to proceed.

21. The paper posed questions to the Group for consideration:

- Question One: At what stage should approval for NKSS cases be sought?
- Question Two: Is there scope to alter these processes?
- Question Three: Is there scope for dual approval for directed altruistic cases?
- Question Four: Is there scope for dual approval for paired/pooled cases?

22. The Group considered the current system and potential changes to the point at which approvals are granted. In the current system paired/pooled cases are assessed by the HTA after they have been matched by NHSBT and are considered by one panel. The Group agreed that there was scope to review and revise this arrangement.

23. The Group agreed that pairs should only be assessed once matched by NHSBT to limit the HTA assessing more cases than are eventually matched.

24. The Group discussed altruistic donors who are part of a chain being assessed once they have been matched. It was agreed that altruistic donors need to be assessed by the HTA before they are matched as they may need to donate to a recipient on the deceased donor list at short notice.

25. The Group agreed that there is scope to review and revise some processes in order to support the changing environment of living organ donation. The Group recognised that one of the reasons for assessing paired cases together was to ensure neither of them extended beyond the period of an approval being valid, which was originally set for six months. It was agreed it would be proportionate to assess paired / pooled cases separately as there is no longer a time limit on the validity of a HTA approval.

26. The Group agreed it would be proportionate to give dual approval to directed altruistic cases so they are able to become non-directed altruistic cases. It was noted that this would only occur for a small number of cases.

27. It was noted that NHSBT has the facilities to enable a change from directed altruistic to non-directed altruistic within 72 hours by running a local matching run.

28. The Group discussed the implications around creating a dual approval system for paired/pooled donation and directed donation, as well as dual approval for altruistic donor chains and directed donation.

29. It was acknowledged that a thorough implementation plan would be required should the Authority agree with the Executive team's proposals. A number of changes would be required to HTA documentation and IT systems as well as communication with IAs and transplant units to implement the changes.

Actions

3. **Executive to take a proposal to the Authority on assessing paired / pooled cases as and when they are submitted in instead of together.**

4. **Executive to take a proposal to the Authority on dual approval for a directed altruistic donation and non-directed altruistic donation.**

5. **Executive to take a proposal to the Authority on dual approval for paired / pooled donation which may turn into a directed donation.**

Emerging policy areas for the HTA and NHSBT

30. The Group discussed some of the emerging policy issues for the HTA and NHSBT and acknowledged the Executive would be taking these issues forward in 2013/14.

31. The Group discussed the issue of donors or recipients travelling for the IA interview and whether video-conferencing could be used for those not prepared to travel for an interview or for surgery. It was argued that in cases where there is clear evidence of relationship, e.g. siblings, there could be some leniency in seeing the recipient and donor together physically.

32. However, it was noted that this may be impractical for the IAs as the technology to hold such interviews may not be available at all units.

33. The Group discussed whether Transplant Units should ask donors in the paired/pooled process what they wish to happen in the event that their organ or part organ cannot be transplanted into the intended recipient. It was noted that this issue does create complex conversations with the donor for the Transplant Units.

34. One option suggested by the Group was to exclude re-implantation as an option for paired/pooled cases.

Action

6. **Executive to work up options for video-conferencing IA interviews and organs that can't be transplanted in the paired/pooled scheme. Options will be presented to the Authority.**

Item 7 – Paired Kidney Exchange with the Republic of Ireland.

35. Allan Marriott-Smith introduced the paper on paired kidney exchange with the Republic of Ireland and requested the views of the Group, in particular with regard to the principle and any practical or operational issues which may prevent the changes from being successfully implemented.

36. The Group discussed the issues around paired kidney exchange with the Republic of Ireland and raised the following questions:

- Will these cases require a panel decision?
- Will other countries wish to join?
- How is the Republic of Ireland implementing the European Organ Donation Directive and Serious Adverse Events and Reactions?
- Could the Republic of Ireland be used as a pilot for future exchange in the European Union?
- What effect will the HTA's requirements have on other countries if in the future we have an EU exchange scheme?

37. It was noted that for urgent liver cases there is a deceased donation sharing scheme set up between the Republic of Ireland and the United Kingdom.

Action

7. **The Executive to consider questions posed by the Group on the subject of paired kidney exchange with the Republic of Ireland and take to the Authority.**

Item 8 – Review of HTA emergency out of hour's system.

38. Stacey Pengelly provided an overview of how the system currently functions and some suggested improvements.

39. The Group agreed with the suggestions in the paper and the Executive will take this forward in the future.

40. The Group discussed the requirement of the Authority to consider cases of 'adult to adult' liver donation and whether this decision could be reviewed. The Group were in favour of this being reviewed by the Executive.

Action

8. **Executive to take a proposal to the Authority that the Executive will assess future Adult to Adult Liver cases.**

Item 9 – HTA position on absence of a presumed genetic relationship.

41. Allan Marriott-Smith introduced the paper to seek the views of the Group on a review of the HTA's position on the absence of a presumed genetic relationship.

42. Allan Marriott-Smith explained that enquiries have been made to the HTA on whether a unit should share information with a donor and recipient when the information is a by-product of tissue typing for organ donation.

43. The Group noted that the HTA's position on absence of presumed genetic relationship is based on the donor being fully informed when consenting to the transplant. However, it was argued that a donor may change their decision to consent and proceed with their donation if they are informed they are not genetically related to the recipient.

44. The Group also discussed how HLA testing is not specifically for testing genetics, so should they be used as such.

45. The Group agreed that the HTA's position on presumed genetic relationship is currently satisfactory; however, it continues to pose issues if units do not adopt the recommendations.

Item 10 – Organ Donation – Six Month Forward Look

46. The Group noted the content of the paper.

Item 11 – Any Other Business

47. It was suggested that the Group could meet in 3 months' time because of volume of complex issues being dealt with if the Executive felt this would be of benefit.

Action

9. Executive to consider holding a meeting in May 2013 if required.

48. Allan Marriott-Smith thanked the Group and closed the meeting.