Minutes of Transplantation Advisory Group

Date	23 May 2018
Venue	Westminster Conference Centre 1 Victoria Street London SW1H 0ET
Protective Marking	OFFICIAL

Present	
Members Anthony Warrens (AW), Chair Amanda Gibbon (AG), Authority Member Lisa Burnapp (LB), Lead Nurse for Living Donation, NHS Blood and Transplant Keith Rigg (KR), Consultant Transplant Surgeon, Nottingham Lorna Williamson (LW), Authority Member Penney Lewis (PL), Authority Member Sam Abdalla (SA), Authority Member Alun Williams (AWi), Consultant Paediatric Urologist, Nottingham Jessica Porter (JP), Head of Regulation Chitvan Amin (CA), Interim Head of Regulation Chris Birkett (CB), Interim Director of Regulation Adam Wells (ACW), Transplant Officer Jennifer Cole (JC) (minutes), Transplant Officer	**Apologies** Michael Heneghan (MH), Consultant Hepatologist, Kings College Hospital

Welcome and apologies

1. AW welcomed all to the meeting, his first as Chair of the group.

2. Apologies were received from MH.

Update on outstanding actions from previous TAG meeting minutes

3. CA updated the group on the outstanding actions from the previous TAG meeting held on 18 October 2017.
    - Action 1: In future, the HTA will inform all TAG members if there is a cancellation.
    - Action 2: Outstanding, The 17 April IA training date had not been shared, as this session was fully booked.
    - Action 3: Incomplete, this was an oversight. CA confirmed that there were no substantive changes to the guidance document. No further action required.
    - Actions 4 – 11: all complete.
    - Action 12: Outstanding as the IA reaccreditation criteria will be reviewed as part of the IA sustainability project.
    - Action 13: The previous IA training session was fully booked therefore an authority member could not attend. Moving forward this will be considered.
    - Action 14: CA spoke to the Living Donor Coordinator (LDC) who agreed to inform the HTA when a donor comes forward via the Donor Advocate Program.
    - Action 15: 'Redirection of an organ to a secondary recipient' policy was shared with LDCs, the LDAT are currently in the process of publishing this to the HTA website.
    - Action 16: The requirement for a second IA assessment is now included in the revised Guidance for Transplant teams and Independent Assessors.
    - Action 17: The Living Donation Assessment Team (LDAT) have developed a procedure whereby urgent cases are highlighted in red. LDCs have been reminded of HTA Panel review timeframes. AW requested to also highlight urgent cases with an asterisk.
    - Action 18: Consideration was given to changing the number of days panels have to review each case. There is no clear business need to make this change at the moment. This will be kept under review.

Action

1. ***LDAT to circulate future IA training dates via Living Donation Newsletter and upload the dates to the website and portal.***
2. ***To review the IA reaccreditation criteria as part of the IA sustainability project.***
3. ***To mark urgent cases with an asterisk and highlight in red for the attention of the Panel.***
4. ***To continuously review whether there is a need to reduce the number of days from ten to five working days to provide decisions on Panel cases.***

Update on IA reaccreditation

4. The group was informed that this process was complete. 119 IAs had passed and 13 were required to undergo refresher training**. All accredited IAs have completed the mental capacity legislation training modules. This is also a mandatory training for accreditation of all new IAs.**

Update on implementation of revised statutory referral letter requirements

5. CA explained the changes to the referral letter and informed the group that from 15 January 2018 all units were asked to use the new referral letter template. As a result, quarter four had been busy due to the increase in enquiries. This was reflected in the business reporting. These issues have now settled and changes have been made based on the feedback from the sector.

6. CA and LB noted that the transition period had been quite challenging but it appeared to have settled.

Sustainability of IA framework and IA accreditation: Update on project

7. JP updated the group on the IA sustainability and accreditation project. The first phase of the project had been to complete a survey of key stakeholders. In total 55 responses were received from IAs and 29 from LDCs. From this data, five main themes had been identified:

    - Recruitment of IAs
    - Payment
    - Reaccreditation
    - Training
    - Governance arrangements

8. Each of these areas were discussed by the group and will be explored more fully and prioritised once the project has been fully scoped.

9. It was agreed that the IA role must be recognised as a key part in the living donation pathway – it is the corporate responsibility of the Trust / Health Board. One avenue to pursue during the project will be to contact relevant Chief Executives to address this point.

10. Reaccreditation – the current system will be reviewed and thought given to developing a risk-based process.

11. Training – Feedback from the survey was positive and the HTA received good feedback from the recent online training. The project will look at what else can reasonably be achieved in terms of accommodating requests for further training.

12. Governance and pay arrangements – The survey confirmed variability in practice across the UK. Approximately 47% of respondents did not have an agreement / contract with the Trust or Health Board to specifically carry out their IA duties, whereas others had honorary

contracts. Consideration will be given as to whether this can be standardised in any way. Some IAs are being remunerated for the role but again there is variability in practice and this will be further explored.

Action

5. ***In addition to the proposed project plan the following points will be considered as part of the project:***
    a. ***LDAT to write to Chief Executives and inform them that it is the corporate responsibility of the Trust / Health Board to sustain required minimum numbers of Independent Assessors at their unit***
    b. ***Consider and develop a risk based light touch approach for IA reaccreditation process***
    c. ***To standardise the governance of IA role across the UK.***

6. ***To liaise with LB and discuss governance and pay arrangements***
7. ***To include GDPR requirements in the project and consider the impact on the IA role.***

Increase in living donor transplantation in the private sector

13. JC spoke about the increase in living donor transplantation in the private sector. The HTA has always received a small number of cases where the living donor transplantation is due to take place in the private sector. However, within the past year in particular, there has been an increase in these numbers. This increase in referrals has largely come from clinical teams working in private wings of NHS hospitals, rather than private hospitals. Overseas patients make up the largest proportion of these donor and recipient pairs.

14. The LDAT manage these cases in line with current HTA policy for the assessment of living organ donation cases. On occasion, the HTA has experienced that these cases are more difficult to assess and can take much longer to review. This is for a variety of complex reasons which include:

15. Reimbursement – In private cases the recipients often directly reimburse expenses of the donor, this can include loss of earnings, flights, accommodation and subsistence whilst in the UK. This can also include paying for the procedure.

16. To ascertain the level of reimbursement covered the HTA has developed a series of questions the IA should ask the donor and recipient to explore reimbursement plans in more depth.

17. Another concern is that reimbursement takes place outside the strict parameters of the NHS reimbursement scheme. This makes it more difficult for the Panel to judge what is fair and reasonable.

18. There is also usually little or no LDC involvement; this means that there is no separation between the clinical team caring for the donor and recipient. In terms of processes, the clinician is not familiar with the HTA requirements and processes and this can often delay the case.

19. LB noted there are examples of good private sector practice and there is a lot of guidance to draw from. The group agreed that it is the responsibility of the Hospitals concerned to assure themselves on a number of these points.

20. The group agreed that the HTA will meet with those centres demonstrating best practice to learn more about this and share learning as appropriate.

Action

8. JP and CA to arrange a meeting with stakeholders in a private hospital and private units in NHS hospitals to discuss best practice in the private sector.

Update Terms of Reference (ToR)

21. AW stated that there did not appear to be any controversial themes and asked the group for their comments.

22. It was agreed thought would be given to whether any additional members of the group were required though there were no strong views that this was necessary.

23. Small amendments were made and the ToR were agreed.

Results of survey of TAG members

24. The group acknowledged the results and found the information useful.

Update on proposed opt out system for deceased organ donation in England

25. JP updated the group on the consultation run by the Department of Health and Social Care about introducing an opt-out system for deceased donation in England, which received over seventeen thousand responses. The Government response is expected to be published in July.

Action

10. To update TAG members at the next meeting on the proposed opt-out system for deceased organ donation in England.

Horizon Scanning / AOB

LB: Update on UK Living Kidney Sharing Scheme

26. LB updated the group about recent changes to the NHSBT Matching Run. From January 2018, all non-directed altruistic donors are entered into the kidney sharing scheme.

27. LB thanked the team for ensuring that non-directed altruistic donor cases are reviewed in time to be registered for the matching run, as these cases must be approved by the HTA before entering the matching run.

28. LB explained that there had been a slight increase in non-simultaneous transplant surgery. Although there are associated risks, transplant units work hard to ensure these are minimised.

Charity that matches donors and recipients

29. JP explained that there are concerns about transparency and how donors and recipients are brought together. There is a suggestion that the information donors are provided with is not entirely accurate.

30. LB stated that further information is required to explore in more detail how donors are recruited and work was underway to explore this further.

Action

11. JP and LB to arrange a meeting to explore the current situation.

Global Kidney Foundation

31. LB explained that the aim of the Global Kidney Foundation appears to be to raise awareness of kidney donations within black and ethnic minority groups but that little was known about the Foundation at this stage.

Closing remarks

32. This was KR's last TAG meeting. AW extended the group's warm thanks to KR for all his hard work over the years and his significant contribution to the group. Alun Williams will replace KR.