
Taking Organ Transplantation to 2020 Oversight Group

Meeting Minutes

Date and Time: Monday 18 March 2019 (13:00 – 16:00)
Venue: Coram Campus, 41 Brunswick Square, London

Participants

Elisabeth Buggins	Chair	EB
Betsy Bassis	Chief Executive – NHSBT	BB
Sheena Booth	Scottish Government (Marketing)	SB
Lisa Burnapp	Lead Nurse for Living Donation – NHSBT	LB
Nigel Burton	Donor Family Network	NB
Anthony Clarkson	Director of Organ Donation and Transplantation - NHSBT	AC
Joan Hardy	Northern Ireland Department of Health	JH
Fiona Marley	NHS England	FM
Holly Mason	Marketing & Campaigns Manager – NHSBT	HM
Patricia McCready	British Association of Critical Care Nurses (BACCN)	PMcC
Roseanne McDonald	NHS National Services Scotland	RM
Gurch Randhawa	Chair – TOT2020 Stakeholder Group	GR
Linda White	Scottish Government	LW
Claire Williment	Head of Consent Legislation Development - NHSBT	CW

In attendance

Lorraine Fahey Minutes

Apologies received

Joanne Allen	ODT Performance and Business Manager – NHSBT
Aisling Courtney	Chair – LDKT2020 Strategy Implementation Group and Northern Ireland representative
Stuart Davies	Welsh Health Specialised Services Committee
Kay Ellis	NHSBT Sponsor, DHSC England
Brid Farrell	Northern Ireland Public Health Agency
Richard Fluck	NHS England
John Forsythe	ODT Associate Medical Director – NHSBT
Dale Gardiner	National Clinical Lead for Organ Donation – NHSBT
Sian Griffin	British Transplantation Society
Sally Johnson	NHSBT
Caroline Lewis	Welsh Government
Fiona Loud	Kidney Care UK
Marina Pappa	DHSC England
Steve Park	Assistant Director of Communications - NHSBT
Jessica Porter	Human Tissue Authority
Susan Spence	NHS Wales
Mike Stephens	Wales representative
Andrea Ttofa	Head of Organ Donation Marketing - NHSBT

1 Welcome, introductions and apologies

- 1.1 EB welcomed members to the meeting and Betsy Bassis, the new Chief Executive of NHSBT, to her first meeting of the Group.

2 Purpose of the meeting

- 2.1 EB summarised the main purpose of the meeting and outlined the contents of the agenda for the afternoon.

3 Oral update on recent activity

- 3.1 AC updated the meeting on current organ donation and transplantation activity. The current expectation is an increase year-on-year for deceased donors but that the total number of deceased donors for 2018/19 will be slightly lower than the target set.
- 3.2 Consent rates were shared with the meeting. It was noted that Wales currently have the highest rates at around 80% combined. London remains the biggest area of challenge around consent as it has been for some period of time. AC reported that work is ongoing to address this issue.
- 3.3 Transplant numbers remain an area of focus. While the expectation is that this year will be the highest number of organ donors recorded in a year, the numbers of transplants have not risen at the same pace. This is likely to be for various reasons impacting upon organ utilisation from donors.
- 3.4 January 2019 is the second highest month on record for deceased organ donor numbers, second only to January 2018.

4 Feedback on Stakeholder Group Meeting

- 4.1 GR provided the meeting with a precis of the conversations that had taken place in this morning's Stakeholder Group meeting. This included an update on conversations around how to make the legislative change in England and work to introduce changes to legislation in Scotland and the Crown Dependencies a success.

5 Legislative Change

- 5.1 CW provided an update on legislative change.
- 5.2 CW outlined the impact that the legislation has had upon cooperation and joint working between the groups supporting the legislation and this will have positive impacts for those involved moving forward.
- 5.3 The Group heard about some of the risks that could impact upon the ability to optimise the impact of any legislation. The Group recognised the need to ensure the wider healthcare community maintain their confidence in, and support for, organ donation.
- 5.4 Novel and Limb Transplants are among the more unusual types of donation for which deemed consent would not apply.

ALL

ACTION

- 5.5 CW's ask of the group is that those involved remain engaged and in contact with NHSBT and this group work to help ensure that whatever support is required to maintain confidence in the legislation and process is maintained. **ALL**
- 5.6 PMcC noted that there is a need to ensure clarity of information and consistency. As a Nurse on an ITU she has not seen any messaging around the change but there is news and updates via social media and other networks. There is a need to use SN-ODs in units and to work with the professional societies in general. AC to consider whether a presentation pack for use in units would be helpful. **AC**
- 5.7 The Group asked if NHSBT could produce updates which the societies could then post upon their sites and use to spread information in an easily accessible way. This would achieve an expansion of understanding in the same way as social media can reach across the populous. It is also important to ensure professional societies outside of the tight Organ Donation and Transplantation community are involved as their members are vital in ensuring referrals. **HM**
- 5.8 CW noted the need to ensure terminology is agreed and can be used across geographical boundaries and national boundaries. Scotland is setting up a campaign advisory group and will then move the process forward. HM provided the meeting with an update on work by NHSBT Comms to increase knowledge and understanding of the legislative change. She shared key media campaign timings and the elements of the campaign with paid media utilised towards the end of the pre-implementation period to maximise impact. AC noted that attempts to utilise existing marketing opportunities to help increase reach could include professional societies, and that NHSBT should consider allowing different or even a collegiate and multi organisational agreed branding for these communications. **HM**
- 5.9 GR shared learning from his work in Spain where communications involve almost exclusively sharing donor and donor family stories as opposed to recipient stories and raised the question whether this should be a part of our learning from their experience. The Group heard about ongoing work to mitigate key negative messages, especially those espoused on social media. It was noted that we will be working to explain that the element of personal choice has not been removed by the change in legislation.
- 5.10 FM invited all to consider how NHS England colleagues can be utilised as opinion formers and advocates. AC outlined how negative news/misinformation could result in spikes in opt-outs. CW explained that the Contact Centre have a team dedicated to looking at this issue and determining whether to intervene. AC explained that curatorship of the @NHS account has been very positive and the potential to use that again should be considered as it has a large and influential set of followers. **HM**

6 National paediatric and neonatal strategy – Update

- 6.1 AC updated the meeting. The Paediatric and Neonatal Strategic Plan had launched formally at joint British Transplantation Society/NHSBT Congress in at the beginning of March. AC explained to the Group that is a strategic plan as opposed to a strategy and will sit within the wider auspices of the post-TOT2020 strategy.
- 6.2 The plan had been conceived because of a recognition that best practice for Paediatric and Neonatal patients is not simply a case of repeating what works for adult patients. There are significant differences in the time taken to proceed to end of life care where a young patient is involved, and this is one of the important differences that needs addressing. AC suggested that ongoing oversight by the group should be considered and explained the differences in Paediatrics which need to be considered if organ donation from these units is to be supported.
- 6.3 The Strategic Plan is available on the website here:
<https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/paediatric-and-neonatal-donation-strategy/>
- 6.4 Paediatric retrievals are impacting upon team members and this will be the subject of research to determine how the team can be best cared for.

EB/AC

7 The Next Strategy

- 7.1 AC presented to the Group and outlined the areas where ‘miss no opportunity for organ donation and transplantation’ could be used to impact upon performance.
- 7.2 LB raised the question whether the pillars of the new strategy negatively impact upon types of non-deceased transplantation if there is a perception that the legislation will mean everyone waiting will receive an organ quickly and therefore do not need to look at living transplantation.
- 7.3 AC outlined the reasons for variations in organ waiting times and the differences across transplanting centres. The meeting then looked at the 5 proposed pillars for the new Organ Donation and Transplantation strategy and considered the challenges that they will pose across the pathway. AC outlined that this strategy will be looking to address the marginal gains that are left in the pathway as the easy and big levers to increase consent rates have already been addressed through the duration of TOT2020. This would now be a question of aiming for perfect performance across the pathway and addressing the local issues that can stop a small number, or one, donation or transplant from taking place.
- 7.4 The meeting requested that the pyramid image showing how the number of deaths in the UK gradually decreases to the eventual number of organ donors be circulated with the minutes.

ACTION

*Post meeting note: See Figure 2.3 of the latest published activity report here: <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/11326/section-2-overview-of-organ-donation-and-transplantation.pdf>
All sections of the latest and previous activity reports are available here: <https://www.odt.nhs.uk/statistics-and-reports/annual-activity-report/>*

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| 7.5 | The potential for 'Organ Donation Champions' on Units who take responsibility for referrals is to be considered. | AC |
| 7.6 | The meeting considered that 'Reducing Inequality for all our Citizens' would be a more appropriate title for proposed pillar 3 of the new strategy. | AC |
| 7.7 | It was noted that pillar 2 should relate to all types of legislation and not just those that introduce opt-out. NI has legislation that supports organ donation but does not have opt-out and that should be recognised within the strategic pillars. | AC |
| 7.8 | The case for creating awards for not missing opportunities to make donation occur are going to be considered. | AC |
| 7.9 | The meeting agreed that Novel Technology should sit within Pillar 1 as part of the new opportunities this pillar supports. | AC |
| 7.10 | The meeting broke into groups to consider the potential opportunities and challenges and the notes will be fed back into the wider consideration process. | AC |
| 7.11 | AC agreed to bring the Strategy back to the next meeting in September 2019 to update the Group. | JA/AC |
| 8 | Minutes of the last meeting and actions not covered elsewhere | |
| 8.1 | The minutes of the July 2018 meeting were agreed. | |
| 9 | AOB | |
| 9.1 | There was none. | |
| 9.2 | EB thanked everyone for their input. | |
| 10 | Date of next meeting | |
| 10.1 | The next meeting will take place on Monday 23 September 2019 in the NHSBT West End Donor Centre Boardroom. | |