

Taking Organ Transplantation to 2020 Stakeholder Group – Minutes

Date and Time: Monday 21st May 2018 (10:30 – 15:30)
Venue: Coram Campus, 41 Brunswick Square, London

Participants

Gurch Randhawa	Chair	GR
Amjid Ali	Lead – Muslim Scholars Engagement Project	AA
Joanne Allen	ODT Performance and Business Manager - NHSBT	JA
Sally Bee	Sally Bee	SB
Andrew Bridge	Transplant Games Event Manager - MLS	AB
Elisabeth Buggins	Taking Organ Transplantation to 2020 Oversight Group Chair	EB
Lisa Burnapp	Lead Nurse for Living Donation – NHSBT	LB
Angela Ditchfield	ODT Diversity Lead Nurse - NHSBT	AD
Alex Forbes	Donor Family Network	AF
Anushka Govias-Smith	NHS National Services Scotland	AGS
Sally Johnson	Director, ODT – NHSBT	SJ
Fiona Loud	Kidney Care UK	FL
Nadia Martini	Team Margot	NM
Yaser Martini	Team Margot	YM
Kirit Mistry (pm)	South Asian Health Action and NBTA joint chair	K Mistry
Kirit Modi	NKF	K Modi
Karen Morgan	Welsh Government	K Morgan
Marina Pappa (am)	Department of Health and Social Care – England	MP
Rosie Pope (am)	Recipient Family	RP
Emma Stapley	NHSBT Senior Communications Officer	ES
Andrea Ttofa	Head of Organ Donation Marketing - NHSBT	AT
Kay Wadey (am)	Donor Family	KW
Claire Williment	Head of Consent Legislation Development - NHSBT	CW

Apologies received

Sam Baker	Scottish Government
John Forsythe	ODT Associate Medical Director – NHSBT
Michelle Mackie	Ipsos
Katy Portell	Organ Donation Ambassador Coordinator - NHSBT

ACTION

- 1 Welcome, introductions, apologies and aim of the meeting**
 - 1.1 GR welcomed attendees to the meeting and reminded the group that we're here to contribute to the behaviour change element of the Taking Organ Transplantation to 2020 Strategy (TOT2020), by sharing and learning from good practice.
 - 1.2 Attendees and apologies received are noted above.
- 2 Setting the scene – 2017/18 record year**
 - 2.1 SJ presented the attached slides, summarising the record-breaking activity in

2017/18.

- 2.2 This generated lots of discussion and it was suggested that the BAME activity report that Statistics and Clinical Studies are currently working on be presented at the next meeting. JA to add to the November agenda. **JA**

- 2.3 SJ summarised her initial thoughts for beyond 2020. The aim is to write a draft to start to consult on before SJ retires and her successor will undertake the consultation. EB clarified that the ODT Sustainable Funding Group have been briefed, but not the Oversight Group yet, but the next Oversight meeting is July.

- 2.4 GR said that at the November Stakeholder Group meeting we will decide what this group can do to take things forward beyond 2020. JA to add to the November agenda. **JA**

3 Behaviour Change Strategy - England

- 3.1 AT presented the attached slides. EB suggested a way that could be a supportive route to hospital boards. EB and SJ to liaise after the meeting. EB also suggested that local people could write to their local NHS chair asking them to respond with what is going to be done to improve organ donation in their local area. **EB/SJ**

4 Living donor kidney transplantation

- 4.1 LB presented the attached slides that included a summary of the January Oversight Group meeting. EB said at the July meeting attendees will update the Oversight Group on their progress since the January meeting.
- 4.2 Following discussion, LB said that she will check if all units are ensuring that thank yous are sent to altruistic donors, as well as living donors who were not able to donate. **LB**
- 4.3 SB will be pitching to This Morning soon and would like ideas for something different about living donation. Ideas to SB please. **ALL**

5 Outcomes from Living Transplant Initiative

- 5.1 K Modi presented the attached slides on the progress and next steps for the Living Transplant Initiative.

6 Opt-out legislation changes

- 6.1 MP attended her first TOT2020 Stakeholder Group meeting and presented the attached slides. SJ followed by saying that it's important for everyone to understand this is about donors and donor families, that the next real challenge is the House of Lords and that what the Bill is called is crucial.

		ACTION
6.2	AT asked MP how DHSC can follow-up on Jeremy Hunt's commitment to get organ donation on the school curriculum. Action for MP.	MP
6.3	The Scottish Government had sent their apologies for this meeting but had circulated the attached paper prior to the meeting. Any questions to Sam Baker or Linda White.	ALL
6.4	CW presented the attached slides. Various requests are included in the slides. Please action accordingly.	ALL
7	Feedback from DHSC Faith Meeting	
7.1	MP gave a verbal update on the faith event that took place on 9 th May. The meeting was in two parts: myth busting and discussion. The key message was that there is lack of trust between local communities and government, and the connection to windrush was made. The Minister is very keen to carry on engaging. K Modi said that he was very pleased to see the Minister there.	
7.2	GR said that Faith Engagement will be a standing item at future TOT2020 Stakeholder Group meetings. Action for JA to add to the agenda.	JA
7.3	GR said that everyone in the room can help get the message right, remembering that the visibility of donors and donor families is vitally important, as it has been shown to increase donation rates in the other countries. GR reminded attendees of the many donor-led organisations that can support such efforts, for example, the Donor Family Network. Action for all.	ALL
8	Organ Donation Campaign Forum	
8.1	ES attended her first TOT2020 Stakeholder Group meeting and presented the attached slides on the Organ Donation Campaign Forum, which is a sister group of this group.	
9	Organ Donation Ambassador Scheme	
9.1	KP unfortunately was not able to attend as planned and sent her sincere apologies to the group. AT summarised the attached slides on the Organ Donation Ambassador Scheme in KP's absence. Action for all to contact KP with any questions and to help spread the word when KP gets in touch about the upcoming London pilot.	ALL
9.2	GR thanked AT for standing in and said that this will be a standing item on the agenda. Action for JA to add to the agenda.	JA
10	NBTA update	
10.1	K Mistry gave a verbal update and said that the NBTA became a Charitable	

	Incorporated Organisation in March. The NBTA currently has 24 members and is considering how they increase membership from grass roots to a national organisation and how they can work more in collaboration. K Mistry will send out information on how people can join.	ACTION K Mistry
11	Update from NHSBT Diversity Lead Nurse – Organ Donation and Transplantation	
11.1	AD gave an update on her first year in post as Diversity Lead Nurse and attendees made suggestions in areas where AD needed advice. AD to get in touch with AT for potential contacts for the Multi Faith Advisory Group.	
11.2	GR said that this will be a standing item on the agenda. JA to add to the agenda.	JA
12	Transplant Games	
12.1	AB attended his first TOT2020 Stakeholder Group meeting and presented the attached slides on the Transplant Games that will be held in Birmingham in August. AB said that the numbers in the slides are even bigger now. AB said that if members of this group were planning to attend part of the event, the Opening Ceremony and the childrens' races are a must-see. It would also be great to take part in the donor run.	
12.2	EB and K Mistry had suggestions and said that they would follow up with AB after the meeting. If anyone has any suggestions to contact AB too.	EB / K Mistry ALL
12.3	During discussions, an Anthony Nolan video was mentioned, that all can view here after the meeting and share accordingly: https://www.anthonynolan.org/bealifesaver .	ALL
12.4	Post meeting note: AB has provided the following links to videos for all to watch and share accordingly. AB is able to provide these in file format; please contact AB if needed. https://www.facebook.com/BritishTransplantGames/videos/1883988658317917/ https://www.facebook.com/BritishTransplantGames/videos/1877891008927682/ https://www.facebook.com/BritishTransplantGames/videos/1862209243829192/ https://www.facebook.com/BritishTransplantGames/videos/1762171163833001/	ALL
13	Review of Terms of Reference	
13.1	The original TOT2020 Stakeholder Group Terms of Reference (version 1.0) had been circulated to the group prior to the meeting for review. GR asked attendees if any changes are required. K Modi pointed out that living donation	

needs to be added.

- 13.2 The latest TOT2020 Oversight Group minutes are now published on the website and it was agreed that the latest minutes from the TOT2020 Stakeholder Group will be published from now on too. JA clarified the process in that the group will be sent the minutes for ratification before they are published and that email addresses will not be included.

JA

- 13.3 JA will draft the changes to the Terms of Reference and send to the group for ratification. The Terms of Reference will then be added to the website.

JA

14 Accuracy of minutes of the November 2017 meeting

- 14.1 There were no objections to the minutes of the last meeting. The minutes are accepted as a true and correct record.

15 November 2017 actions not covered elsewhere on the agenda

- 15.1 AT gave an update on NHS 70 that was mentioned at the last meeting. See <https://www.nhs70.nhs.uk/> for how to get involved and continue to support through social media.

ALL

16 AOB

- 16.1 None

17 Summary of 'ask' of stakeholders

- 17.1 GR said that all the 'asks' were captured throughout the meeting and summarised that there are lots of opportunities in the next six months. GR asked stakeholders to carry on with what they're doing and said a big thank you to everyone.

18 Date, time of location of next meeting

- 18.1 The next meeting will be held in London on Monday 19th November 2018. JA will confirm the venue and timings in due course. Please all note this date in your diaries in the meantime and let JA know if you're able to attend or not.

JA

ALL