

Taking Organ Transplantation to 2020 Stakeholder Group – Minutes

Date and Time: Monday 18 March 2019 (10:30 – 12:30)
Venue: Coram Campus, 41 Brunswick Square, London

Participants

Gurch Randhawa	Chair	GR
Betsy Bassis	Chief Executive – NHSBT	BB
Sheena Booth	Scottish Government (Marketing)	SB
Paul Bristow	Kidney Care UK	PB
Andrea Brown	National Kidney Federation (NKF)	AB
Elisabeth Buggins	TOT2020 Oversight Group Chair	EB
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
Holly Mason	Marketing & Campaigns Manager – NHSBT	HM
Yuri Matischen	MLS / Transplant Sport	YM
Roseanne McDonald	NHS National Services Scotland	RM
Kirit Mistry	South Asian Health Action and NBTA joint chair	K Mistry
Kirit Modi	National Kidney Federation (NKF)	K Modi
Katy Portell	Organ Donation Ambassador Coordinator - NHSBT	KP
Linda White	Scottish Government	LW
Claire Williment	Head of Consent Legislation Development - NHSBT	CW

In attendance

Lorraine Fahey Minutes

Apologies received

Amjid Ali	Lead – Muslim Scholars Engagement Project
Joanne Allen	ODT Performance and Business Manager – NHSBT
Sally Bee	Sally Bee
Angela Ditchfield	ODT Diversity Lead Nurse - NHSBT
Kay Ellis	NHSBT Sponsor, DHSC England
Brid Farrell	Northern Ireland Public Health Agency
John Forsythe	ODT Associate Medical Director – NHSBT
Sian Griffin	British Transplantation Society
Caroline Lewis	Welsh Government
Fiona Loud	Kidney Care UK
Nadia Martini	Team Margot
Yaser Martini	Team Margot
Marina Pappa	DHSC England
Steve Park	Assistant Director of Communications - NHSBT
Jessica Porter	Human Tissue Authority
Jan Shorrock	Give a Kidney
Andrea Ttofa	Head of Organ Donation Marketing - NHSBT

1 Welcome, introductions, apologies and aim of the meeting

- 1.1 GR welcomed all to the meeting and provided an overview of the objectives of the Group. The importance of working together to support organ donation was emphasised and agreed.

2 Legislative Change – update, campaign and group work

- 2.1 CW presented to the meeting.

CW set out the legislative process and the fact that Royal Assent has been granted for the English legislation which is to be known as Max and Keira's law. It was noted that preparing the legislative change has encouraged and grown relationships within the organ donation field as different groups worked to support and influence the process. A good example being the relations between NHSBT and faith groups that existed before but have grown through the process. There will be a minimum of 12 months between assent and implementation.

NOTED

- 2.2 Representatives of the Scottish Government reported on the proposed legislative change currently being considered before the Scottish Parliament. At the most recent hearing no amendments had been suggested and the bill had the overwhelming support of members

- 2.3 CW reported on the Isle of Man legislative process which commences in April 2019 but noted that is agreed they may seek for the legislation to go live in Autumn 2019

- 2.4 The NHS App and its implications for the ODR were outlined. EB asked whether consultation documents would be mailed to the group members? CW agreed that she will mail all with news as these documents go live. The meeting noted the importance of ongoing engagement to ensure supportive messaging is received in consultation exercises.

CW

- 2.5 K Modi informed the meeting that the HTA are looking at the organ donation process and there is a need for organ donation professionals to support the HTA as they move forward. GR to feedback this to the Group HTA representative and CW agreed with the idea that GR writing as the chair would be welcomed by the HTA.

GR

- 2.6 LB explained that there is a transplant advisory group on HTA that LB is a member of and is happy to take issues forward through that route. It was noted that Sept 2019 being the date of the next Stakeholder Group meeting is too late to invite someone from HTA and influence. GR to write to HTA to reflect the mood of the meeting.

GR

ACTION

- 2.7 HM provided the group with a brief update re developing the public awareness campaign to support legislative change in England. The ambition is to encourage all to make their decision and share that with loved ones.
- 2.8 Campaign concept is 'Pass it On' agreed through focus groups across the UK. The campaign emphasises that everyone still has a donation choice and that it should be shared.
- 2.9 Paid media activity to be utilised close to implementation: Jan to April 2020.
- 2.10 Stakeholder support is key in communicating change; this is because trusted community stakeholders can inspire and motivate citizens to donate in a way which more remote campaigns may not.
- 2.11 HM explained that real life stories will be used in the campaign wherever possible. There will be a door drop but it will be targeted and not to all households.
- 2.12 KM stated that DVLA messaging states that in Wales no action is required and raised the question is that correct messaging? AC outlined that the messaging from NHSBT will always be to tell family your decision.
- 2.13 The meeting then split into group work to consider how to change the culture around organ donation. The feedback from this session was captured and will be shared with the Marketing Team. GR summarised the feedback. **HM**
- 2.14 It was noted that education is a vital part of normalising donation in the community. Questioned when/if a strategy to embed education would be possible using the legislation as the driver. Action for the Stakeholder group: collectively seek to encourage education through contact with DfE and other contacts to influence. **ALL**
- 2.15 KM asked if there could be consistency around the terminology used for the law; Max and Keira/Opt-Out/Presumed Consent are all in use in different areas and this can be confusing. AC agreed to take this away and work with others to consider options. **AC**
- 3 Community Investment Scheme - brief update**
- 3.1 HM explained that some of the successful applicants for the community investment scheme will be invited to the September meeting to discuss the benefits of involvement and their experiences. **HM/JA**
- 4 Next Steps for Development of the New Strategy**
- 4.1 AC presented to the meeting. High level themes were shared with an explanation that these are starting points for a year of discussion and are

capable of being altered if feedback indicates this would be beneficial. AC then outlined the 5 initial ideas for the pillars of the strategy.

- 4.2 The timeline for the new strategy is that the initial strategy will go to the NHSBT Board and will then go out to consultation until Autumn ready for publication in 2020.
- 4.3 KM asked is this a 5yr strategy? AC explained that this is a UK strategy which will be subject to agreement by the UK governments in the same way as TOT2020 and that it will be a 5 yr strategy. There is the potential to combine living and deceased transplantation within this strategy and give both equal statuses.
- 4.4 K Mistry emphasised the need for BAME issues to be embedded through the next strategy and in no way a periphery on the agenda.
- 4.5 AC outlined that the key levers have been used, so the marginal gains and small wins will need to be addressed. A separate session to consider the strategy will be considered.

AC

5 Living Donation Update

- 5.1 LB introduced to the meeting the new living donation communications which are within NHSBT brand guidelines but are updated to better reflect how living donation occurs.
- 5.2 The intention is to work with partners in 2020 and onward to measure the living donor experience and for the first time understand what living donors experience.
- 5.3 Outlined the altruistic donors' impact and the fact that 1000 donations have now taken place.
- 5.4 LB outlined the work that has been undertaken to engage with hard to reach communities both in terms of ethnic and social criteria. LB thanked all involved in the project for their help in making the progress achieved thus far.

6 Minutes of the Last Meeting

- 6.1 GR requested that any alterations to the circulated minutes for November 2018 please be passed to JA for action and amendment.

**ALL/
JA**

Post meeting note: No amendments received by 31 May; therefore, the minutes are accepted as a true and correct record.

7 AOB

- 7.1 The question was raised as to where or how transplant recipients would be recognised in the post 2020 strategy? It was noted that recipients are currently

ACTION

covered from within the Organ Utilisation Strategy but this is not the same as the Organ Donation and Transplantation Strategy. AC to consider whether recipient care is something which is within the remit of the strategy to deliver upon and consequently if it can sit within this strategy document

AC

8 Summary of 'ask' of stakeholders

- 8.1 GR thanked everyone for their contributions and enthusiasm throughout the meeting.

9 Date, time and location of next meeting

- 9.1 The next meeting of the Stakeholder Group will take place on Monday 23 September 2019.