Taking Organ Transplantation to 2020 Oversight Group

Meeting Minutes

Date and Time: Monday 15 January 2018 (10:30 – 15:00)
Venue: Coram Campus, 41 Brunswick Square, London

Participants

Elisabeth Buggins	Chair	EB
Joanne Allen	Performance and Business Manager, ODT – NHSBT	JA
Chitvan Amin	Human Tissue Authority	CA
Léonie Austin	Director, Marketing and Communications - NHSBT	LA
Richard Baker	Chair – Clinical Reference Group, NHS England	RB
Lisa Burnapp	Lead Nurse for Living Donation – NHSBT	LB
Aisling Courtney	Chair – LDKT2020 Strategy Implementation Group and Northern Ireland representative	AC
Jon Gulliver	NHS England	JG
Sally Johnson	Director, ODT – NHSBT	SJ
Fiona Loud	Kidney Care UK	FL
Jen Lumsdaine	Living Donation Programme Lead for Scotland and British Transplantation Society representative	JL
Kate May	NHS Wales	K May
Roseanne McDonald	National Services Scotland	RM
Karen Morgan	Welsh Government	K Morgan
Dafni Moschidou	Department of Health – Living Donation	DM
Gurch Randhawa	Chair – TOT2020 Stakeholder Group	GR
Mike Stephens	Wales representative	MS
Emma Wilbraham	Department of Health	EW
Claire Williment (pm only)	Head of Transplant Development, ODT - NHSBT	CW
Ryan Wilson	Northern Ireland Government	RW

Apologies received

Sam Baker	Scottish Government
Brid Farrell	Northern Ireland Public Health Agency
Richard Fluck	NHS England
John Forsythe	Medical Director, ODT – NHSBT
Kay Hawkins	Paediatric Intensive Care Society
Joe Magee	Northern Ireland Government
Alex Manara	Faculty of Intensive Care Medicine
Fiona Marley	NHS England
Lorna Marson	British Transplantation Society
Gary Masterson	Intensive Care Society
Patricia McCready	British Association of Critical Care Nurses (BACCN)
Jeremy Mean	Department of Health
Paul Murphy	National Clinical Lead for Organ Donation – NHSBT
Pamela Niven	Scottish Government
Jessica Porter	Human Tissue Authority

ACTION

1 Welcome, introductions and apologies

1.1 EB welcomed members and new attendees to the meeting. Apologies received are listed above.

2 Purpose of the meeting

2.1 EB explained the purpose of the meeting as outlined on the agenda and acknowledged that it is different across the four nations. EB also informed the group that she had invited Kirit Modi to this meeting but he was unable to attend due to a prior commitment.

3 Understanding success and accelerating progress in living donation

3.1 LB presented the attached slides and set the scene for living donation across the UK. This generated questions about the proportion of patients from black and Asian communities in the shared schemes and the experience of altruistic donors. It was agreed this would feed into today's discussions.

3.2 AC presented the attached slides and explained that it's the cultural norm to be a living donor in Northern Ireland. Donors feel special and then become advocates so Northern Ireland doesn't need to overtly recruit donors. AC emphasised that the donor assessment is very fast with a one day assessment. More than 700 donors have been through the one day assessment and nobody has said that it's too quick. AC also emphasised the dialysis cost savings due to living donation, ie spend to save.

3.3 MS presented the attached slides for Wales and explained that changes are required if targets are to be achieved. With some changes 20pmp may be possible in Wales. MS asked if we can move away from 26pmp because it sounds like we're failing when we're not, eg can we emphasise other parts of the strategy such as % pre-emptive? The Welsh Government is going to help publicise living donation. K May also pointed out that patient choice is very important.

3.4 JL presented the attached slides for Scotland and outlined the living donation project underway with Scottish Government, commissioners, clinicians and patient representatives. Scotland have increased to 17 pmp in the past year and will aim for sustained increases towards 2020.

3.5 JG presented the attached slides and explained the difficulties in that there are 52 renal units and 10 commissioning hubs in England.

3.6 EB asked attendees to form groups of threes/fours with people they don't normally work with.

4 Group discussions – living donation

4.1 EB asked the five groups to each discuss the following three topics in turn:

- What have you not heard today that will help solve the problem (ie new ideas)?
- What have you heard today that should be adopted everywhere?
- What needs to be done and who can make that happen?

4.2 The following ideas were put forward by group A:

1. Shortened work up time (perhaps including a one stop shop).
2. Timing of approach pre-transplant message rather than pre-dialysis.
3. Nephrologists attitudes to transplantation.

ACTION

4.3 The following ideas were put forward by group B:

1. Investment in nursing: Regional lead living donor co-ordinator who would be accountable to commissioners. This nurse would lead the living donor teams and co-ordinate regional initiatives.
2. Early and consistent education for all recipients - specialist nurse commitment for transplant first early education - separate role from a living donor co-ordinator and could be achieved by additional support and education in low clearance renal nurse teams.

4.4 The following ideas were put forward by group C:

1. Financial incentives such as CQUINs, also consider support from KQUIP (Commissioners/Govt/NHSBT/Community)
2. Role of patient organisations, information, peer support (Kidney Health Partnership Board – clinical/patient)
3. One stop shop / speed (NHS England, Clinical Ref Group could promote via specifications, role for link nephrologists in this)
4. Can we consider the role of Oversight Group in clearly promoting living donation?
5. Language and timing - no more ‘pre-dialysis’ clinics, use a new term such as ‘kidney clinic' (Renal Association? British Renal Society?)
6. How to calibrate consistency/quality of messaging to patients and donors.

4.5 The following ideas were put forward by group D:

1. Difficulties encouraging a small (but considerable) number of nephrologists to engage with the concept of live donor first. This might be improved by a more rigorous performance management system (perhaps using pathway metrics).
2. The lack of ‘up-front’ money to set up a more streamlined assessment process (e.g. a ‘one-stop’ clinic). It would be up to commissioners to decide to spend the money upfront in order to save on dialysis costs further down the line (perhaps a few years down the line).
3. The option of a ‘one-stop’ assessment clinic should be available in every transplant centre in the UK. This would require commitment from the clinical leads in each centre and investment from commissioners.
4. Making sure that the information patients are given on transplantation (in particular live donor transplantation) is delivered by the right person i.e. someone with up-to-date experience of transplant risk and benefits (definitely not by ‘pre-dialysis’ nurses). A national Live donor peer review programme may help with this (or some other form of external scrutiny/inspection).
5. Ensuring any investment is targeted in the right direction. This might be linked to point 4 above and there may be some scope to include charity funding in there.

4.6 The following ideas were put forward by group E:

1. Improve donor experience / make easy – influence whole pathway (Living Donor Lead Clinicians Group, NHS England – reimbursement – By March 2019)
2. Making sure donor and their families are ambassadors (LD 2020, SIG, LD reported experience – March 2019)

		ACTION
	3. Positive messaging and positive language (LD 2020, SIG – set up, professional clinical network) 4. Skills training (using UK Living Kidney Donation Network effectively)	
5	**Action plans from living donation group discussions**	
5.1	EB summed up that it's the belief of clinicians that is the key. If they believe it, their patients will believe it. The 'message' is driven by clinical belief.	
5.2	EB asked if people could think of a title for what we could do with living donation because a consistent ambition makes the strategy much easier. Any ideas to be fed back via JA. Some ideas put forward in the meeting were 'Transplant First' and 'Let's make it easier to give a kidney'.	All
5.3	LB said that it would be great if we can do as much of this as we can. Needs reality of thinking about investment in the right place in a targeted way. One size doesn't necessarily fit all.	
5.4	Action for AC to send RM the funding analysis. Action also for AC to write up the savings.	AC AC
5.5	In response to EB's question about what happens next, LB said the Implementation Group are meeting in April. The Implementation Group will look closely at the ideas put forward today, form an action plan and assign time frames. LB said that if it turns out that we can't do some of the ideas, at least we should be held to account to try. AC said that the Commissioners are very important.	Implementation Group
5.6	Action for Commissioners to determine what they are going to do and send to JA/LB.	Commissioners
5.7	This can be picked up at a future ODT Sustainable Funding Group meeting too.	JA
6	**Vote of confidence of achieving 2020 living donor targets**	
6.1	EB asked the group to indicate how confident they are that the UK will achieve 26 living donors pmp following today's discussions. The main response for 2020 was 50%, but when asked the same question of the year 2025, most people were 90-100% confident.	
6.2	SJ said that perhaps Trust level targets would make people think.	
6.3	MS questioned if 26 pmp is sustainable.	
6.4	CA from the HTA pointed out that at the moment there is the lowest number of Independent Assessors nationally. AC responded that these are paid in Northern Ireland; RM said that they are going to start reimbursement in Scotland and MS said they are paid in Wales. Secondly it is crucial that the referral centres and transplant centres factor in the HTA decision timeframe at the point when the case is referred to the HTA, the HTA has seen an increase in requests to provide last minute approvals.	
7	**Deceased donors and transplants**	
7.1	SJ presented the attached slides. All agreed that the published targets should be retained but that more realistic numbers would be used for financial planning purposes, as per the slides. EB clarified to the group that the ODT Sustainable Funding Group discusses priorities.	
8	**Progress update on opt-out**	
8.1	CW presented the attached slides regarding NHSBT's role. EW said that	

there have been approximately 8000 responses to the England consultation so far. EW said that the plan is to analyse the results and aim to provide the Government response by the summer recess (July).

8.2 LA emphasised the importance of using lots of different channels to reach all groups.

8.3 Sam Baker had sent her apologies for the meeting but provided the following update ahead of the meeting for Scotland: The Scottish Government is continuing its work to develop the Organ and Tissue Donation Bill with assistance from the Scottish Donation and Transplant Group's sub group on opt out. The Bill Team is also working with analysts and stakeholders to develop the Bill's accompanying documents and impact assessments. Work to conduct focus groups and meetings with stakeholders, such as children, adults with learning disabilities and faith groups has now been completed and is being taken into account in the Bill's development and the impact assessments.
RM also said that there is a commitment by September 2018 to introduce legislation in Scotland.

8.4 RW said Northern Ireland are not pursuing opt-out, but are promoting organ donation instead. Northern Ireland plans to reassess in five years.

8.5 The DBD consent rate is starting to increase in Wales but it is difficult to determine what has made the difference. There was a new media campaign before Christmas that had some good prime time slots so it will be good to see what impact that has.

8.6 SJ felt that no overrides should be equivalent to a DNR decision.

8.7 LB said that the British Transplantation Society is also going to run a consultation.

8.8 CW asked to formally note a thank you to Philip Worsfold at the Department of Health.

9 Ratify TOT2020 mid-point review report

9.1 The draft version of the TOT2020 mid-point review report had been circulated to members prior to the meeting. LA clarified that this is more of a matter of record to be available for information rather than drawing attention to it.

9.2 LA and EW will agree the date of publication. LA/EW

9.3 Sam Baker had fed back prior to the meeting regarding the possibility of incorporating living donation into the report. It was decided that an equivalent living donation paper could be published at the same time and the reports can cross reference each other.

9.4 The group agreed that the circulated report is ready to be published with no changes.
Post meeting note: One minor change has been made since the meeting, ie all the country logos needed updating on the back cover. JA

10 Review Terms of Reference for Oversight Group

10.1 Attendees reviewed the Terms of Reference and made minor changes including mention of the Living Donor Kidney Transplantation 2020 strategy. It was also agreed that the minutes will start to be published, ie always displaying the latest minutes only. The minutes therefore need to be circulated and signed off by the group in a timely manner after the meeting. JA

ACTION

The Terms of Reference will also be published. JA

10.2 The Terms of Reference will be version controlled and will contain an updated membership list. The current membership was agreed by attendees.

10.3 *Post meeting note: The updated Terms of Reference (version 2.1) including current membership list are attached, following updates from members since the meeting.*

11 Minutes of the last meeting (August 2017) and actions not covered elsewhere

11.1 The minutes were accepted as a true and accurate record apart from:

1. Paul Bristow attended the August 2017 meeting representing Kidney Care UK but is not recorded on the minutes.
2. The action on Page 5 regarding CQUINs is for NHS England not Department of Health.

11.2 Regarding the CQUIN action on Page 5, JG reported that the CQUIN is not currently under consideration for early referral. SJ said that discussions are happening at Regional Collaborative meetings. JG said that it would be sensible to do a peer review first.

11.3 Regarding the transplant capacity report action on Page 8, CW said that it has gone to transplant units and said that it now needs to go out wider. CW clarified that it's not intended for publication.

11.4 Regarding the never events action on Page 9, EW reported that a serious incident framework is due to be published next week.

12 AOB

12.1 Alex Manara had sent his apologies for the meeting but asked that members were made aware that the Devastating Brain Injury Pathway has been published in the British Journal of Anaesthesia, and is also available on the websites of the Professional bodies involved. Members can also contact Alex Manara directly.

13 Date of next meeting

13.1 The next Oversight Group meeting is scheduled for Monday 16 July 2018 at the NHSBT West End Donor Centre.