James Lind Alliance
Priority Setting Partnerships

James Lind Alliance Priority Setting Partnership – Renal Transplant

Steering Group Teleconference, September 11th 2014, 16:00-17:00

Participants

Leanne Metcalf (LM) **Chair**	James Lind Alliance (JLA)
Simon Knight (SK)	Centre for Evidence in Transplantation (CET)
Peter Morris (PM)	Centre for Evidence in Transplantation (CET)
Angela Beale (AB)	Patient Representative, NKF
Katriona O'Donaghue (KD)	Centre for Evidence in Transplantation (CET)
Rachel Hilton (RH)	British Transplantation Society (BTS)
Fiona Loud (FL)	Patient Representative, BKPA
Simon Ball (SB)	British Renal Society (BRS)
William Beale (WB)	Carer and donor representative , NKF
Sandra Regan (SR)	JLA Project Manager, Oxford Biomedical Research Centre (BRC)

Apologies

Keith Hodkinson (KH)	Patient Representative, KRUK
Graham Lipkin	Renal Association (RA)
Lorna Marson	Kidney Research UK (KRUK)

Minutes

Agenda Item		Actions
1	**Minutes of last meeting** • Following apologies, the Minutes of the last meeting were reviewed. No matters were arising as the Agenda covers all points. The Minutes were accepted.	
2	**Update on Partners** • SR had reviewed the files and correspondence relating to partners and reported that: - Addenbrookes Kidney Association are happy to disseminate information without formal partnering; - The British Association of Social Workers are not able to formally partner, but are happy to post information on their knowledge hub on the web; - The UK Renal Pharmacy Group referreed us to a local contact, Andrea Devaney, and we are awaiting further contact. - Some 12 organisations have not responded to earlier approaches. • Discussion concluded that: there is a good mix of partners so not to keep chasing those that have not responded – this can be reassessed according to the spread of survey responses; NHS BT should be followed up; Renal Patient View and UK Renal Registry should be approached.	**1. SK to pick up contact with Andrea Devaney re UK Renal Pharmacy Group and with NHS BT (see item 4 below)** **2. SR to provide FL with information to take to UK Renal Registry meeting on 3/10** **3. WB/AB to approach Renal Patient View**

3	**Feedback from the pilot survey** • SK talked the Steering Group (SG) through the report of the pilot survey. On the whole, feedback was positive with regard to design accessibility and wording. Where there was negative feedback concerning the design, it was felt that this was due to the person not having clearly read the preamble as no-one else seemed to have a problem. • SK raised 3 specific issues – (i) asking respondents to be more specific in order to provide questions that research can answer; (ii) encouraging more respondents to leave their e-mail addresses; (iii) whether the scope of the PSP should be revisited in light of some feedback concerning deceased donors. • Discussion concluded that: (i) it is up to the SG to reframe the questions to make them more suitable for research to answer, as far as is possible depending on the questions asked; (ii) changing the text around future contact to collect more e-mail addresses is a good plan; (iii) the scope should not be revisited, as this would make it too broad to manage. • In discussing the publicity (see item 4 below), it was felt that it would be good to add a question to understand where people heard about the survey, without making it too long.	**4. SK to make necessary changes to survey**
4	**Publicity for the survey** • The SG reviewed the two poster designs that SK had drafted, and agreed that the one with the white top was clearer. It was agreed that reference to families should be included, and contact details provided in case anyone would like to request hard copy of the survey. It was agreed that SR's contact details be used. SK will also prepare leaflets/ cards to be distributed to transplant units. • Discussion followed on how best to reach out through the >20 transplant units. It was agreed that NHS BT is a route to identifying key contacts at each centre (probably Transplant Nurse Co-ordinators), and SK will contact Chris Watson, the Chair of the NHS BT Kidney Group, as well as James Neuberger, the Assistant Medical Director (copied to Kamann Huang, the Clinical Support Administrator).	**5. SK to make necessary changes to poster & prepare cards/ leaflets** **6. SK to contact NHS BT**
5	**Survey launch date** • LM reminded the SG that the launch had been anticipated as being around the beginning of September with the survey open for two months. • Discussion considered that: it would be good to be open for 2 months and to close before Christmas, aiming for the next stage in the New Year; the survey can be open in advance of any active promotion to partners; patient magazines and medical society newsletters will take the longest to reach and need reminders/ prompts. • It was concluded that the survey would open on October 1st, with	**7. SR to send SK the current list of partner status**

	promotion ongoing for two months, reviewing along the way and adjusting as necessary.	
6	**AOB** • SR reported on the discussions between the Biomedical Research Centre and NETSCC on the recommendations from the PiiAF work. If the SG is agreeable, it would be good for the PSP to track the origins and outcome of the carer and patient voices. The survey is already designed to collect these two groups' questions separately, and the DUETs framework will provide the structure for understanding the origins/ outcomes of all the voices in the PSP. The SG agreed that it would involve little extra work and would be happy to do this. • The question was raised of whether to keep the questions that were contributed by the pilot. Discussion concluded that the pilot respondents should be given the chance to take the survey as this would allow them the freedom to express themselves fully, which they may not have felt able to do in the pilot. If they choose not to do so, there is no objection to the pilot questions being included. • The issue of whether it is possible to identify multiple responses to the survey from one contributor was raised. SK clarified that Google Forms, in which the survey has been constructed, does not allow IP address to be seen, and so cannot track the originator – this would only be known if they choose to leave their e-mail address. It was concluded that, even if someone did try to bias the results by multiple contributions, the ultimate outcome is based on the interim voting process.	
7	**Next meetings** • It was agreed that the next meeting should be around half-way through the survey, and SK will send out a doodle poll.	**8. SK to send out a doodle poll**