

James Lind Alliance Priority Setting Partnership – Renal Transplant

Steering Group Teleconference, 22nd July 2014, 10:00hrs - 11:15hrs

Participants

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| <p>Leanne Metcalf (LM) Simon Knight (SK) Peter Morris (PM) Angela Beale (AB)O Katriona O’Donaghue Rachel Hilton (RH) Keith Hodkinson (KH) Fiona Loud (FL) Simon Ball (SB) Rosamund Snow (RS) William Beale (WB) Hilary Cullen (HC)</p> | <p>Chair James Lind Alliance (JLA) Centre for Evidence in Transplantation (CET) Centre for Evidence in Transplantation (CET) Patient Representative, NKF Centre for Evidence in Transplantation (CET) British Transplantation Society (BTS) Patient Representative, KRUK Patient Representative, BKPA British Renal Society (BRS) PiiAF Carer and donor representative , NKF Oxford Biomedical Research Centre (BRC) Coordinator</p> |
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Minutes

| Agenda Item | Discussion | Actions |
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| 1 | <p>Apologies No apologies received</p> | |
| 2 | <p>Update on recruitment of Partners (Hilary Cullen)</p> <p>Prospective partner organisations have been contacted, with several organisations confirming their involvement as partners, with specific contact details, agreement for their logos to be used, and interest in assisting with publicity and survey dissemination confirmed. Other organisations, including those with volunteer members have taken some time to respond, or have not given full contact details.</p> <p>HC will circulate an up to date list of confirmed partner organisations, those who have expressed an interest but full contact details not yet confirmed, and those organisations who have been contacted, but no response received so far. The contact list continues to grow, and the Steering Group are asked to let HC know of have any further contacts to invite to participate in the PSP.</p> <p><i>Current confirmed partners include:</i> Alport UK British Association for Paediatric Nephrology Give a kidney Kids Kidney Research</p> | |

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| | <p>Oxford Transplant Foundation PKD charity South West Thames Kidney Fund South West Thames Kidney Foundation</p> <p>Contact made but pending confirmation of partnership (eg: contact not available) :</p> <p>Kidney Wales NBTA (<i>patient organisation for black, Asian and ethnic minorities</i>) Renal Social Workers - BASW Renal Special Interest Group Transplant Sport</p> <p>Invitation sent to the following organisations, awaiting response:</p> <p>AKPA –Addenbrookes Kidney Patients’ Association British Renal Society British Society for Histocompatibility and Immunogenetics British Society for Immunology Darlinda's Charity for Renal Research Human Tissue Authority Intensive care society NHS England (Director of Renal services) NHSBT Royal College of Nurses - Renal Nurses Transplant Alliance Transplant Support Network</p> <p>SK gave an update on other partners recruited to the PSP:</p> <ul style="list-style-type: none"> • Scottish Kidney Federation • Carrel Club – (Transplant Surgeons in Training) <p>FL suggested that the Renal Pharmacy Group be contacted and invited to participate also.</p> <p>HC will circulate the updated list of contacts for all organisations. Steering Group members are invited to forward further suggested organisations / contacts to HC for follow up.</p> | <p>Action 1: SG members to forward further contact details to HC for further follow up.</p> |
| <p>3</p> | <p>Feedback and final agreement on the draft survey (Simon Knight)</p> <p>SK thanked the SG members for their feedback on the draft survey and as far as possible comments have been reflected in the amended version. There was one ‘transplant’ example of a submitted survey research question given in the draft survey. SK asked for comments and whether the SG were happy with the examples as set out.</p> <p>FL commented that she was unhappy to include an example question relating to ‘compliance with anti-rejection drugs regime’.</p> <p>SK advised these were just example / representative questions, but open</p> | <p>Action 2: SK to redraft the survey for the (a) remove the ‘transplant’ example; (b) add a feedback questionnaire</p> |

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| | <p>to suggestions.</p> <p>Following further discussion it was agreed that the ‘transplant’ example question be taken out, and when the survey was piloted, one of the ‘feedback’ questions for those participating in the pilot would ask if the examples were helpful in completing the survey.</p> | |
| 4 | <p>Pilot strategy for the draft survey (all)</p> <p>LM advised that a pilot study on the survey was helpful to check the accessibility / user-friendliness of the survey. It would need only a small number of a diverse group of people to complete the survey, and suggested that if each member of the Steering Group could ask 3 – 5 people of the group of people they represent (clinician / organisation members) to complete the survey this would be enough.</p> <p>SK will prepare a short covering email which can be sent to all those asked to participate in this ‘pilot’, with a link to the dummy survey. As it is holiday time, they will be asked to respond in about 3 weeks, and a reminder will be sent in 2 weeks time to anyone who has been sent this covering email and ‘pilot survey’ link, to ensure that all pilot responses are received, and reviewed promptly.</p> <p>The responses to the pilot survey will be reviewed and discussed at next Steering Group teleconference.</p> | <p>Action 3:</p> <p>Each Steering Group member to Approach 3 – 5 individuals (clinician / patient / carer) to ask them to complete the pilot survey.</p> <p>SK to draft a covering email to be sent to each person volunteering to complete the pilot survey, asking for their assistance, giving the survey link, and a response time.</p> |
| 5 | <p>Publicity strategy for initial survey (all)</p> <p>LM / SK outlined the possible ways to publicise and promote the survey. Each partner will be asked to assist through their communication links and networks.</p> <p>HC will prepare a list of contact person/ address or link from each of the partner organisations already identified, and include their different means for publicising the survey, to include: newsletters, news feeds, conferences, social media.</p> <p>A discussion raised the following points:</p> <ul style="list-style-type: none"> • Paper versions of the survey would be available, or could be printed out from the web site. • Posters and leaflets may be helpfully displayed in clinics • Articles in local / organisational magazines could be written / sent to the organisations for inclusion. • A QR (Quick Response digital link) could be set up for display | <p>Action 4:</p> <p>HC to prepare a list of contacts for each partner organisation, and confirm the routes for publicity for each organisation, so that appropriate information circulated (news, announcements etc)</p> |

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| | on posters which could then be accessed via visual links on phones giving information | |
| 6 | <p>PiiAF update (Rosamund Snow / subgroup)</p> <p>RS summarised the discussion that was held by the Steering Group subgroup on 2 July 2014, as set out in the document circulated with the agenda: “Measuring the impact of patient and public involvement in the Kidney Transplant PSP”.</p> <p>It may not be possible to consider further all the four main issues as outlined in the document above. Most on the call expressed a preference for option 4 (Impact of different types of survey participant on suggested priorities), with varying second-choice preference for either option 1 (Impact of JLA PPI on funding decisions) or option 3 (Impact of patient/carer involvement on what counts as a treatment uncertainty). There was general agreement that option 2 (Impact of patient/carer involvement in general within the JLA steering group) would be difficult to quantify and assess.</p> <p>RS suggested that she discuss internally the available funding to assess how many of these options could be explored in the impact assessment exercise. If funding is not available for all 3, a vote by email will be taken among the Steering Group members to confirm which issues were considered priority for further work.</p> <p>RS thanked the Steering Group for their input and advised that she now had much to put to the PiiAF team when considering further work.</p> | <p>Action 5:</p> <p>RS to investigate how many options could be explored and report back to the Steering Group</p> |
| 7 | <p>Any other business</p> <p>The next teleconference would be held in early September, to be confirmed in due course, once the deadline for the pilot survey has been set.</p> | |