

KIDNEY TRANSPLANT PSP – FIRST STEERING GROUP MEETING MINUTES

Minutes of the meeting of the Kidney Transplantation PSP Steering Group held on Monday 19th May 2014, from 11.00am–4.00pm, at the Royal College of Surgeons of England (Drexler Seminar Room).

In attendance:

Leanne Metcalf - LM	Chair (James Lind Alliance)
Simon Knight - SK	(Centre for Evidence in Transplantation – CET)
Peter Morris - PM	(Centre for Evidence in Transplantation – CET)
Angela Beale - AB	(National Kidney Federation – NKF)
Graham Lipkin - GL	(Renal Association – RA)
Rachel Hilton - RH	(British Transplantation Society – BTS)
Keith Hodgkinson - KH	(Kidney Research UK – KRUK)
Fiona Loud - FL	(British Kidney Patient Association – BKPA)
Jennie Popay - JP	(PiiAF)
Rosamund Snow – RS	(PiiAF)
Katriona O’Donoghue - KO	Minutes (Centre for Evidence in Transplantation – CET)

Apologies:

Lorna Marson - LMa	(Kidney Research UK - KRUK)
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1. Welcome and Apologies for Absence

LM welcomed the group to the first Kidney Transplant Priority Setting Partnership (PSP) Steering Group meeting. She noted apologies from LMa.

2. The JLA and the PSP Process

LM introduced the Priority Setting Partnership (PSP) as a partnership between patients, carers, health professionals and researchers. It is a collaborative project to identify unanswered questions in kidney transplantation (treatment uncertainties), and to prioritise these in the order of importance to inform a future research agenda and attract research funding. The James Lind Alliance (JLA) is an initiative that brings together patients, carers and clinicians to identify and prioritise the top ten uncertainties (unanswered questions) about the effects of treatments. The JLA is managed and coordinated by the National Institute for Health Research.

LM explained the PSP process as one which involves four stages; Consultation, Collation, Ranking/Prioritisation and Question Development. Consultation will involve an initial survey to elicit treatment uncertainties which is advertised to all appropriate stakeholders. Collation will be the interim in which duplicates will be removed from the survey results and the group will establish the broad emerging themes. The literature will be reviewed to confirm these themes are genuine uncertainties. Genuine uncertainties will be coordinated into the next phase and entered into the DUETs (Database of Uncertainties about the Effects of Treatments). Ranking/Prioritisation will involve prioritising the list of uncertainties into a second survey. In this survey, participants will rank the list of uncertainties by importance. The findings from the second survey then feed into a final prioritisation workshop where representatives of researchers, patients, carers and health professionals come together to discuss and agree on the top ten treatment uncertainties. The

process concludes with a Question Development phase where these top ten uncertainties are packaged up and developed into fundable research questions by the Steering Group.

LM confirmed that the second survey will be promoted widely after the initial survey and it will be targeted at a range of individuals – the range of stakeholders who could be seen to have an opinion on the relative priorities of unanswered kidney transplant research questions is likely to be broader than those who feel able to submit raw uncertainties in the initial survey. She assured the group that the James Lind process is well respected and the data collected would include facts as well as opinions, as it also draws on published scientific literature.

RH stressed the need to draw on findings of previous prioritisation exercises in the same area. This will prevent any confusion felt by participating individuals who have contributed to such exercises. KH emphasised the importance of allocating funds wisely with the focus to be on benefitting the patients. In addition, the necessity for research groups to work together and not to be inhibited by an ulterior agenda. FL suggested the need to ensure that information is not duplicated but also not to prejudice the opinions of the participants. She stressed the process would need to include a clear explanation of how this PSP has built on previous research.

3. Roles and Responsibilities of the Steering Group

LM explained the roles and commitments of the Steering Group; to devise and agree on the protocol, identify and invite potential partners to become involved with the process, identify and collate treatment uncertainties, prove the uncertainties to be unknowns against the current literature, priority setting and the dissemination of results. The Steering Group itself will commit to the research and to be the fundamentals for the process. The amount of involvement of each individual within the Steering Group will vary, depending on their schedule. The members of the Steering Group will be required to support each other during the process and divide tasks accordingly. The JLA will offer support, facilitation and guidance during the process. The Steering Group will be required to demonstrate their commitment to the aims and values of the James Lind Alliance by affiliating to the process on the JLA website.

ACTION: All members of the Steering Group are required to affiliate to the James Lind Alliance at www.lindalliance.org.

LM stressed the need for transparency within the Steering Group and asked each member to declare any competing interests that may affect the process. FL felt that every member of the Steering Group would have a conflict of interest at some point during their career due to the nature of representing organisations that publicly advertise a certain point of view. It was agreed that all members of the Steering Group would declare any current or future conflicts of interest that they felt warranted declaration. When in doubt as to what constitutes a conflict of interest, the group agreed to declare the matter as one.

ACTION: All members of the Steering Group are to sign the Declaration of Interests Form, declaring any competing interests. This form is to be returned to SK as a matter of urgency.

4. Finalising and agreeing to the Terms of Reference

It was agreed by all members to act as a collective group to manage the Kidney Transplant PSP. The Steering Group agreed to formalise what had been discussed and indicate agreement to follow the Steering Group Terms of Reference.

ACTION: All members of the Steering Group are to indicate agreement to follow the Steering Group Terms of Reference. This can take the form of a confirmatory e-mail to SK once the Terms of Reference have been updated with the timescales.

5. Background to and current status of the Renal Transplantation PSP, including the Public Involvement Impact Assessment Framework (PiiAF)

SK explained the background to the PSP and role of the Centre for Evidence in Transplantation (CET) in the PSP activity; to collate existing literature by looking at systematic reviews to decipher where the lack of research is, confirming the list of uncertainties and creating a balanced view. The CET is involved in all aspects of organ transplantation. The Kidney PSP is first of its kind so the success of this research may lead on to further PSP's conducted with other organs. He stressed the importance of getting all relevant officials involved in supporting the Kidney PSP. SK clarified the current budget of the project to be £20,000. He requested that the Steering group minimise expenses where possible. FL recommended that the British Renal Society (BRS) be approached and invited to join the Steering Group as a matter of urgency.

6. Review and Discussion of the Draft Protocol

LM recommended defining the scope of the PSP early in order to specify limitations. She explained that some previous PSP's have looked specifically at treatment uncertainties (the original remit of the JLA process), while others have looked more broadly at causes, prevention and/or after effects. The Steering Group agreed the intended audience for this PSP to be; anyone who has ever had a transplant at any point (therefore including those that have returned to dialysis) and those that are actively on the waiting list. The Steering Group agreed to broaden the range of people the PSP encompassed to also include children and living donors. The scope needs to be finalised to reflect the breadth of the kidney transplant research included in the PSP as a result of this.

ACTION: SK is to draft a document detailing the scope of the PSP.

LM explained the role of partners in the PSP as organisations that can reach and advocate for the intended participants of the PSP, and will work on getting those participants involved. She specified that individuals with a professional or personal interest could be considered, not only those that represent an organisational body. Individuals or organisations that had conflicts of interest could be involved in an observational capacity only. Suggested partners included; the British Association for Paediatric Nephrology (BAPN), Human Tissue Authority (HTA), National Health Service Blood and Transplant (NHSBT), The Scottish Kidney Federation and the Kidney Wales Foundation. It was decided that the scope of partners should not be extended further than the UK, therefore excluding the European Society for Organ Transplantation (ESOT).

The Steering Group agreed that the British Renal Society (BRS) should be invited to join the Steering Group.

ACTION: SK is to approach Simon Ball from the British Renal Society and invite him to join the Steering Group.

ACTION: Members of the Steering Group are to send the contact details of possible partner affiliates to SK.

ACTION: SK is to follow up on Partner leads; Professor Chris Watson and Professor James Neuberger at NHSBT.

GL voiced concern about how the participants in the survey would know which questions to ask. He suggested the group consider providing education in the form of focus groups. LM clarified that focus groups have been used successfully before in previous PSPs. She noted that patients prefer an unrestricted opportunity to ask the questions that are important to them. She suggested the Steering Group to consider the way the questions will be worded in the survey. RS stressed the importance in phrasing the questions carefully so as the participants of the survey feel that their answers will be valued. She explained that from her knowledge of a previous PSP in diabetes, patients asked intelligent and necessary questions.

ACTION: LM is to send to all members of the Steering Group examples of other PSP initial surveys.

LM noted that a pilot version of the initial survey would need to be developed and refined by the Steering Group, initiated by SK in the first instance, in the next six weeks. Once the Steering Group has agreed its broad content, this pilot survey would be sent out by each member of the Steering Group to 3-5 specific individuals from their audience groups that they know would give meaningful feedback in a timely way. The returned responses should help to finalise the survey and enable the Steering Group to be confident that it would elicit meaningful raw treatment uncertainties. LM cautioned that the pilot survey may be agreed to be ineffective by the Steering Group and completely reworked, hence a short deadline for a first draft.

ACTION: SK is to draft an initial survey for the Steering Group to comment on, which will be used to gather the raw unanswered questions about kidney transplantation from both patients and clinicians (the same survey for both). This can be modelled on other PSP surveys.

It was agreed that the survey should be administered electronically and as a pdf that can be printed and administered by hand. The aim of the survey is to reach as many individuals as possible from all areas. It was agreed to aim for 1000 responses.

7. Timeline

LM advised the Steering Group that the complete JLA process should take 12-18 months. The process began in October 2013 with LM and SK, thus the aim would be to reach the final workshop around this time next year (May/June 2015). A subgroup of Steering Group members will need to be present for the final workshop.

The Steering Group agreed to sign the terms of reference and protocol by the end of this month (May). Over May/June the Steering Group will work on getting all relevant partners involved in the process and inviting relevant members from BTS to join the Steering Group.

The Steering Group agreed to schedule a teleconference every 4-6 weeks with the first one tentatively set for the end of June. It was noted that not all members will be required to attend the teleconferences, provided the teleconferences were attended by SK, LM, some clinical representatives and some patient representatives (see later).

While teleconferences will be utilised to ensure the project remains on track, the Steering Group agreed to schedule a face to face meeting for September/October. This will be the next face to face meeting and the second of four (today being counted as the first). This meeting will be to finalise the

promotion/marketing aspects of the PSP (i.e. the communications plan, including the website), the survey and the partners that will be involved.

SK will aim to produce a draft survey for the group to critique by June/July. The group will finalise a copy to pilot by the end of July before the summer holidays. The pilot survey will be reworked as required and the communications plans finalised over the summer, and the Steering Group will aim to launch the initial survey in September/October.

The Steering Group agreed for the first survey to tentatively open in October and to close around November (being open for responses for 6-8 weeks). From September onwards the group will look at the literature and start to pull together the survey responses as they come in in order to cluster them into themes and check and validate them as genuine uncertainties. The refining of the uncertainties will continue until the end of January and will involve confirming the uncertainties and removing those that are duplicated. A prioritisation survey will follow asking the participants to prioritise the reduced list of ten uncertainties.

All members of the Steering Group agreed to the provisional timeline.

ACTION: SK and LM are to finalise the provisional timeline and send it out to all members of the Steering Group.

8. Patient involvement impact assessment framework (PiiAF)

JP explained the Patient involvement impact assessment framework (PiiAF) as guidance to help researchers assess the impacts of involving members of the public in health and social care research. She emphasised the usefulness of the framework alongside widespread and growing interest in assessing this impact. She identified two parts to the process; exploring the values of a range of factors that might shape public involvement and providing support to develop an impact assessment plan. JP advised the timescale of the process to develop this plan to be a maximum of 4-6 weeks. RS will be in charge of the process but will be supported. The first part of the process should take a day (possibly half a day) with RS. The second part of the process will be the longest, taking the remainder of the time (up to 6 weeks).

The members of the Steering Group agreed to the PiiAF process, deciding that a subgroup would lead on the process and present the details to the larger Steering Group. The subgroup would comprise of approximately three members from the Steering Group.

ACTION: The Steering Group is to read through the PiiAF documentation. Any expression of interest to be a member of the subgroup is to be e-mailed to SK.

9. Roles and Resources

LM concluded the PSP as well equipped to be a successful process. She affirmed the Steering Group to be comprised of a good level of expertise in all areas, particularly in comparison to previous PSPs. She indicated an opportunity for members of the Steering Group to be more involved in certain aspects of the process such as data analysis and marketing. Training will also be offered for the Database of Uncertainties about the effects of treatments (DUETs), the system that records all unanswered questions.

ACTION: Steering Group members are to e-mail SK if they would like to get more involved in certain aspects of the PSP process or undertake DUETs training.

ACTION: LM is to send out success stories from previous PSP studies.

10. Launching and promoting the PSP

SK directed the group to the Kidney transplant PSP website. KH highlighted the duplication of work from previous prioritisation exercises. He reasoned for the website to be marketed at the correct audience, to entice their involvement in the PSP. He suggested the aims and aspirations of the study to be prominent on the home page. GL concurred that there is a perception from viewing the website that we are undermining previous research. He stressed the importance of demonstrating collaboration with previous research groups and to incorporate their knowledge and information. RH indicated that the relevant organisations involved in this PSP and previous research should have their branding evident on the website.

It was agreed by the Steering Group that the website should acknowledge relevant organisations. It was also agreed that the picture graphics on the website should be updated with more recent attention-grabbing photographs.

ACTION: SK is to get the logos of all organisations (previous and current) involved with the PSP and to include these on the website.

ACTION: Members of the Steering Group are to provide images to SK that could be used on the website.

ACTION: LM is to circulate to the Steering Group a series of links to other PSP website examples.

ACTION: Members of the Steering Group are to e-mail any further suggestions/ideas for improving the website to SK and SK is to action these improvements (in addition to those discussed in the meeting).

It was decided that an initial awareness meeting (event) was not feasible within the current budget. It was agreed that partners should be invited to become involved with the Kidney PSP via e-mail. Face to face meetings will be organised with particularly sensitive organisations, where required. Partners will be specified the level of their participation and agree to be involved. Partners will be required to affiliate to the James Lind Alliance at the same website as the Steering Group (www.lindalliance.org).

ACTION: SK is to coordinate an invitation to be sent out to all partners to join the PSP process.

11. Teleconference/meeting dates and administration

It was agreed that teleconferences will be scheduled for every 4-6 weeks. Critical members must attend. The Steering Group agreed for the critical members of the group to be defined as two patients, two clinicians, SK and LM. The date for the next teleconference will be tentatively set for the end of June, and then every 4-6 weeks thereafter. Dates will first be coordinated against the availability of SK and LM and possible dates will then be circulated to the rest of the Steering Group to agree on. The Steering Group will look at using BT MeetMe or Powwownow for teleconferences.

Initial agendas for future meetings will be decided by LM and SK and will be sent out to all members of the Steering Group one week prior to the scheduled meeting. Meeting minutes will be circulated to all members of the Steering Group within two weeks on conclusion of the meeting. DoodlePoll

will be used to set dates for teleconferences and the dates for three teleconferences will be set at any one time.

ACTION: SK and LM are to coordinate and circulate a tentative date for the next teleconference meeting (i.e. end of June), plus the July and August ones.

12. Any other business/closing remarks

LM agreed to provide a copy of her slides to all members of the Steering group. SK will update any absentees on the details of the meeting.

ACTION: LM is to send out the slides from her presentation to the Steering Group.

ACTION: SK is to update individuals that left the meeting early or who were absent.