Introduction to the James Lind Alliance and priority setting
The James Lind Alliance (JLA) is a non-profit making initiative which was established in 2004 with the aim of enabling groups of patients/carers and clinicians to agree together on priorities in treatment uncertainty research. The JLA thus facilitates Priority Setting Partnerships (PSPs) in particular conditions.

Each PSP consists of patients/carers and their representatives, and clinicians, and is led by a Steering Group. Collaboration of this sort whereby patients and clinicians together set the research agenda is extremely rare, but vital in drawing issues to the attention of research funders which might not otherwise be suggested or prioritised.

The role of the PSP is to identify questions about treatment which have not been answered by research to date, and to then prioritise these. An interim priority setting exercise takes place over email/by post, and a priority setting workshop is then convened where partners debate and finally arrive at a top ten list of shared uncertainties which are most important to them.

The aim is then to “translate” these uncertainties into research questions and obtain funding for that research.

Further details are at www.lindalliance.org.

About the Steering Group
The Steering Group is responsible for coordinating and implementing the activity of the PSP. Drawing on members’ expertise and networks, the Steering Group will help encourage membership to the wider PSP and, where members have the capacity and expertise, will carry out the practical work needed to collate the interim and final priority setting exercises. The Steering Group is also responsible for ensuring research funders are made aware of the final top ten uncertainties.

Membership of the Steering Group includes representatives of organisations for patients and clinicians, as well as JLA staff. Like the rest of the PSP, Steering Group members are expected to participate in the priority setting exercise.

Tasks
The Blood Transfusion and Blood Donation PSP Steering Group members are expected to participate in a number of specific tasks during the course of the priority setting process:

- Monthly telephone conference calls to update on progress
- Publicising the initiative to potential partners to encourage them to join the PSP. This includes advising on membership of the PSP (to ensure a wide and representative group of patients and clinicians) and emailing contacts to invite them to participate
- Managing the collection of treatment uncertainties from patients, clinicians and existing literature
- Managing interim priority setting. This involves working with the JLA to develop the interim priority setting questionnaire
- Collating the results of interim priority setting and producing an “interim top 20-30” to take to the final priority setting workshop
• Participation in the final priority setting exercise: a one-day workshop which brings partners together (one representative per organisation) to debate, rank and agree a final top ten
• Publicising the final top 10 uncertainties to the sector and to research funders. This includes working with the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC) to develop applicable priorities into research questions, as well as preparing academic publications.

Level of involvement and resources
Steering Group members are asked to contribute, at a minimum, their expertise and their time. Basic involvement, as listed above requires:
• an interest in the initiative and outcomes being pursued in the project
• a broad understanding of project management issues and the approach being adopted
• commitment to working with other members respectfully and constructively
• advocacy for the project’s outcomes
• prompt feedback on prioritisation materials
• participation in the monthly telephone conference calls
• the sharing of networks and contacts for membership of the PSP
• participation in the one-day final priority setting workshop, anticipated as being in January 2017
• taking the time to bring the top ten blood transfusion and blood donation uncertainties to the attention of funders

A Steering Group teleconference will be quorate with the presence of Leanne Metcalf, Mike Murphy plus 2 clinical representatives and 2 patient representatives. Leanne will be mindful of the importance of patient representative views.

Administration
This includes making arrangements for all meetings and workshops, and ensuring:
• requests for agenda items are discussed with the group
• papers will be available at least a week before meetings
• meeting notes will be circulated within two weeks

E-mails will be circulated in cc rather than in blind copy.

Publications
Agreement will be needed on how to acknowledge Steering Group members in publications; individual members will not publish or present in their own right or without agreement of the other members.

Timescales
Inaugural meeting
Monday 5th October 2015
Monthly telephone conference calls
Dates to be confirmed
Face to face Steering Group meetings
July 2016, January 2017
Presentation to Annual BBTS Conference
September 2016
Interim survey
September/ October 2016
Final Workshop
January 2017
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The wider aims and responsibilities of the Blood Transfusion and Blood Donation PSP are set out in the JLA Protocol.