

Miscarriage Priority Setting Partnership

Background and Steering Group Terms of Reference

Introduction to the James Lind Alliance and priority setting

The James Lind Alliance (JLA) is a non-profit making initiative that 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 that 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 10 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.

The PSP will work with the UK Database of Uncertainties about the Effects of Treatments (UK DUETs - www.library.nhs.uk/duets) to promote access to the uncertainties identified by the Partnership.

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 that can reach and advocate 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 Miscarriage 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.
- Working with UK DUETs to develop the Miscarriage module.
- 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 and UK DUETs to develop the interim priority setting questionnaire, based on the uncertainties in the Miscarriage module in UK DUETs.
- Collating the results of interim priority setting and producing an “interim top 25-30” 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.

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
- taking the time to bring the top ten Miscarriage uncertainties to the attention of funders

Administration

- For a monthly telephone conference call or face-to-face meeting to be quorate, there must be a minimum of two clinician and two patient representatives in addition to Leanne Metcalf (LM) and Matt Prior (MP).
- The agenda for meetings will be available at least one week before the teleconference/meeting.

- The agenda will be drafted by MP with input from LM, and circulated by MP. There will always be an agenda item for 'Any other business' to cover additional points of discussion from steering group members which is not otherwise covered in the agenda.
- Minutes will be circulated within two weeks of the meeting.
- A DoodlePoll will be used to set teleconference dates and face-to-face meetings for the duration of the PSP and these are likely to take place on Mondays and Wednesdays due to LM's availability.

Timescales

See Miscarriage PSP timeline (which can be found in the Miscarriage PSP Protocol - Appendix 1)

Key contact

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The wider aims, responsibilities and activities of the Miscarriage PSP are set out in the JLA Protocol and its accompanying timeline (Enc B).