

The coeliac disease Priority Setting Partnership

Steering Group – background and terms of reference

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 work together to agree priorities for health research. The JLA facilitates Priority Setting Partnerships (PSPs) in particular health areas.

Each PSP consists of patients, carers and their representatives, and clinicians, and is led by a Steering Group. Collaboration between patients, carers and clinicians to 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 which have not been answered by research to date, and to then prioritise these. The first stage is an online survey to patients, carers and clinicians, asking for unanswered questions about coeliac disease. These questions will then be assessed to check they are in scope for the PSP and checked and verified as true uncertainties. An interim prioritisation exercise then takes place to shortlist the uncertainties, before a priority setting workshop is then convened where participants debate and finally arrive at a Top 10 list of shared unanswered questions, or uncertainties, which are most important to them.

The aim is then to turn these uncertainties into research questions and for members of the Steering Group to work with researchers and research funders to obtain funding for that research.

All uncertainties are displayed on the JLA website. Further details about the JLA and PSPs are at <http://www.jla.nihr.ac.uk/>

The coeliac disease Priority Setting Partnership

The background and wider aims and responsibilities of the coeliac disease PSP are set out in the JLA coeliac disease PSP protocol.

About the Steering Group

The Steering Group is responsible for overseeing and guiding the activity of the PSP. Drawing on members' expertise and networks, the Steering Group will help encourage membership to the wider PSP and, where capacity permits, will carry out the practical work needed to collate the interim and final priority setting exercises. The Steering Group is also responsible for helping raise awareness of the final Top 10 uncertainties, including among research funders.

Membership of the Steering Group includes individuals and representatives of organisations which can reach and advocate for patients and clinicians, as well as the JLA Adviser. Steering Group members with direct relevant experience as patients, carers or healthcare professionals are invited to participate in the priority setting exercise.

Role of Steering Group meetings

Steering Group members are asked to contribute, as a minimum, their expertise and their time. Steering Group members are asked to adhere to the following principles:

- 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.

Specifically, Steering Group members will:

- attend monthly telephone conference calls. To be effective in its decision making, each meeting should be represented with at least a clinical, patient and research element
- attend face to face meetings, or if unable to attend, submit comments ahead of the meeting. Where a Steering Group member is unable to attend a meeting, decisions made at the meeting will be respected
- respond promptly with feedback on project materials by responding to emails
- share networks and contacts for membership of the PSP
- publicise 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, carers and clinicians) and emailing contacts to invite them to participate
- have oversight of the collection of treatment uncertainties from patients, carers, clinicians and existing literature
- oversee and lend expertise to the data management process, including agreeing the scope and process for data checking
- have oversight of the interim priority setting stage
- verify the shortlisted questions to be taken to the final priority setting workshop
- participate in the final priority setting exercise (if job role qualifies them to represent the views of patients, carers or clinicians). This is the one day workshop which brings patients, carers and clinicians together to debate, rank and agree a final Top 10. It is only attended by patients, carers and the healthcare professionals or support workers who actively work with them
- be involved in the development of the Top 10 coeliac disease treatment uncertainties into research questions for funders
- work with the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC) and other research funders to develop the priorities into research questions.

It is agreed that for this coeliac disease PSP, patient/carer representatives and healthcare professionals (to include representation from general practice, gastroenterology, dietetics, paediatrics) will need to be present at Steering Group meetings/teleconferences. To prevent a delay in progress, if anyone cannot be present they will be consulted after the meeting for their views, to ensure they agree with any proposals and/or collective decisions.

Declaring interests

Steering Group members are asked to declare any interests relevant to the coeliac disease PSP. There is a form to be completed by each member of the Steering Group and the interests of each member will be listed and shared among the group. This is to encourage a culture of openness and transparency. Relevant interests may be professional, personal or related to an interest in or involvement in clinical research.

PSP Coordination

The PSP will be chaired by Maryrose Tarpey JLA Adviser. Heidi Urwin is the PSP lead and Katie Stokes is the PSP Co-ordinator. This includes making arrangements for all meetings and workshops, and ensuring that:

- requests for agenda items are discussed with the group
- papers are available at least a week before meetings
- meeting notes are circulated within two weeks.

Timescales

The coeliac disease PSP first Steering Group meeting took place in London, 5 May, 2017. We propose that the final prioritisation workshop takes place in Q1, 2018.

Key contacts

PSP Chair: Maryrose Tarpey, JLA adviser

PSP Lead: Dr Heidi Urwin

PSP Clinical Lead: Professor David Sanders

PSP Co-ordinator: Katie Stokes

PSP Information Specialist: Ann Daly