



James Lind Alliance Priority Setting Partnership on Rare Inherited Anaemias – Data Manager opportunity

Background

James Lind Alliance (JLA) Priority Setting Partnerships (PSPs) bring together patients and carers, members of groups that represent their interests and the health professionals who treat them, to identify and prioritise questions that they want research to answer. PSPs are led by a steering group with an independent Chair, the JLA Adviser.

The aim of the PSP is to identify current uncertainties in the diagnosis, treatment, management and care delivery of people of all ages with rare inherited anaemias, and the impact on their families, from patient and clinical perspectives;

A survey to collect patients', carers'/families' and healthcare professionals' uncertainties/unanswered questions in accordance with their stated aims was launched in October 2016 and will close in December. A Data Manager is sought to analyse the resulting data, form it into researchable questions, and check them against systematic reviews and guidelines to ascertain those that have been adequately answered by research, and those that have not.

There is the possibility that the same person might also analyse the results of another rare diseases PSP, but this is not certain and if it is required, the timing is not currently known.

It is anticipated that there would be some questions that apply across rare diseases more generally, so having one Data Manager will allow for understanding of any such overlaps and formation of that third category of questions. The work will be overseen by the Steering Groups, who will also input and lend technical expertise where required and the PSP Lead(s) will be available to guide and supervise.

Tasks

- Clean and organise the raw data from the initial online PSP survey(s)
- Prepare taxonomies (categories/codes)
- Examine each submitted uncertainty and allocate into taxonomy, noting duplicate/similar submissions to be combined, and those that are out of scope
- Format in-scope submissions into PICO format where possible (questions that include the Patient, Intervention, Comparator and Outcome)
- Identify relevant systematic reviews and guidelines, and any other relevant sources of evidence
- Check the formatted questions against the evidence base, noting true uncertainties and those that are answered by a reliable evidence base
- Prepare long list(s) of verified uncertainties for interim prioritisation survey(s)
- Prepare the final spreadsheet(s) of the verified uncertainties, including any amendments made during the prioritisation processes, for entry on the JLA website
- Provide regular updates of progress to the JLA project team and Steering Group(s) and work within overall timescales agreed across the PSP(s)

More detailed guidance and examples are available in the JLA Guidebook (www.jla.nihr.ac.uk).

Competencies

- Experience and skills of working with Excel
- Critical appraisal skills



- Ability to manage and categorise qualitative data that requires information to be extracted from it
- Ability to carry out qualitative analysis of the categorised data to produce clinical research questions
- Experience of medical terminology
- Attention to detail – methodical and organised
- Able to work to deadlines
- Ability to communicate complex data to both patients, carers and clinicians
- Familiarity with JLA process would be helpful, but not mandatory
- Awareness of the PSP health area would be useful, but not mandatory

The timescale/contract

- We estimate that this work will equate to 15-30 non-consecutive days (depending on whether one or two PSPs are involved), and would negotiate with the individual if additional support beyond the contract is required
- The work would start in January 2017, and would require varying degrees of input to conclude after the final workshop of the PSP(s) with a final piece of work to prepare the data for entry on to the JLA website at the end of the projects. The final workshop for the Anaemia PSP is currently estimated to be held in the summer of 2017.
- This type of work could be conducted alongside a full time occupation such as a DPhil study, provided the research supervisor agreed for the student to undertake this piece of work. There may be scope for participation in the development of journal articles
- The work would be carried out through a contract between the Partnerships and the individual, via the Oxford University Hospitals Foundation Trust, at an agreed rate.

If you are interested

- Please send your CV and background information about your interest in the post to Judith Rogers, Assistant James Lind Alliance Project Co-ordinator, NIHR Oxford Biomedical Research Centre, at Judith.Rogers@ouh.nhs.uk
- If you would like an informal discussion about the role, please contact Judith in the first instance.
- We would like expressions of interest by December 9th 2016.