



**James Lind Alliance
Tackling treatment uncertainty together**

Project Specification

“A description of research priority setting, (and the presence of patient and public involvement in priority setting), amongst the main UK clinical research funders”.

**Commissioned by the James Lind Alliance in 2007/2008
July 2007**

1. Context and background

Research* priority setting** and patient and public involvement in priority setting, is at the core of the JLA philosophy, and work programme. One of the JLA’s most important objectives for April 2007 – end of March 2008 is:

“Explore with Clinical Research Networks how research priorities are identified”.

In 2006 the UKCRC undertook a survey¹ of public and charitable funding of Research, and analysed research portfolios, particularly the spend across domains of research. Whilst this is an immensely useful piece of work, that has been used in some JLA activity, the UKCRC Report didn’t attempt to answer how decisions to fund particular domains of research had been made, and if patients of public groups/individuals were involved in these processes.

There is a body of evidence addressing some of the issues in priority setting and, in particular patient and public involvement in priority setting. This is referred to in section 5.1 below, and the last pieces of significant work were published in 2004. There are also no significant studies that address core issue that concerns the JLA, i.e the shared priorities in clinical treatment uncertainties.

The research landscape has changed considerably since then, with the advent of the NIHR, UKCRC, the UKCRN and more recently the Office for Strategic Co-ordination of Health Research (OSCHR), and further changes in the Research Assessment Exercise process.

With this in mind, and with moderate funds at our disposal, the JLA Monitoring and Implementation Group, and partners from the JLA Strategy and Development Group, UKCRC and UKCRN have explored how we could increase our knowledge and understanding of how clinical research bodies set their priorities, and whether/how patients and the public are involved in this work.

* For the purposes of this specification, research means clinical trials and systematic reviews or reviews (as this is the focus of the James Lind Alliance).

** For the purposes of this proposal, priority setting means at a strategic level; topic/disease/question selection and calls for research proposals; and more operationally how these research proposals are awarded.

This could be a very large and complex project, and therefore it is proposed that a preliminary scoping exercise be undertaken. The work would be descriptive only and give the JLA Strategy and Development Group a more informed picture of research priority setting, and patient and public involvement (PPI) in this activity across a range of key funders.

At this stage the work will not assess or evaluate priority setting, and PPI in priority setting, as part of this work.

However the results of this mapping could trigger a proposal for more in depth work, maybe alongside a systematic review of the JLA bibliography² should a research partnership, and funding be secured.

2. What would be the benefits of the scoping exercise?

- The JLA will be able to make informed decisions about how its priority setting approach (DUETs and Working Partnerships) could fit in with other approaches, and where it would add value to decision-making.
- By having more clarity about how clinical research priorities are set, the JLA can optimise the point at which 'worked up' shared clinical and patient priorities about uncertainties are presented to potential research funders.
- It could strengthen the relationships between the JLA and clinical research funders and extend our networks.
- It could be added to the evidence base being developed by the UKCRC and UKCRN of patient and public involvement in health research.

3. Objectives of the scoping exercise:

- To establish meaningful contact with key people from the suggested list of clinical research funders below. We anticipate the assistance of the Strategy and Development Group in this task.
- Suggested list of potential participating organisations:
 - Association of Medical Research Charities
 - A 'large' health research charity – e.g. Cancer Research UK, and a 'moderate' health research charity – (*suggest ££ income per annum as a determining factor*)
 - Dept of Health – NIHR (*need to choose the Central Commissioning Facility funding streams that have most relevance to JLA objectives*)
 - NCRN
 - One of the Clinical Studies Groups in the UKCRN
 - MRC
 - Cochrane Collaboration
 - Centre for Reviews and Dissemination
 - Wellcome Trust
 - ABPI – *as a strategic group for industry*
 - Co-ordinating Centre for Health Technology Assessment
 - NICE
 - ESRC/BBSRC
 - HEFCE
 - A small selection of JLA Affiliates who fund research (*especially any patient/public led groups*)

- To obtain, with each of these identified clinical research funders, information and descriptions of current priority setting activity, and descriptions of any PPI involvement in this work.
- Produce a report for the Strategy and Development Group, the DUETs Working Group, the Monitoring and Implementation Group, the UKCRC PPI Projects Group, the UKCRN PPI leads group, AMRC PPI Working Group, and the wider JLA network.

5. Methods

1. A rapid appraisal of the key existing published evidence on research priority setting, and patient and public involvement in priority setting, including the AMRC Peer Review Statement³, the 9 directly relevant papers in the JLA Bibliography², the important paper by Oliver et al with the HTA⁴, M O Donnell and V Entwistle⁵. Include the original work for the informal review of priority setting methods undertaken as part of the Asthma Working Partnership activity⁶. Checking the entries of the UKCRC Activities Log for examples of PPI in research priority setting. Liaising with the UKCRC PPI Project Group to check for any duplication of existing work.
2. Develop a topic guide for the interviews from this initial work – consider a set of descriptors to help structure the report e.g.

Initiators: researchers, research programmes, users
User participants: individuals, organised groups
Degree of user participation: consultation, collaboration, user led
Forum for priority setting: written (e.g. consultation/ survey), face-to-face, interviews, focus groups, etc), mixed, large/ small numbers
Context of priority setting: national/ international/ regional/ local; academia/ community; focus of research (e.g. health condition, type of intervention, type of research)
Methods for decision-making in priority setting: formal consensus development, committee meeting procedures, voting etc
Need for differentiation between commissioned and responsive funding
Adapted from suggested text by Sandy Oliver

3. Approach the suggested clinical research funders with a letter/email of statement of intent and an invitation to participate. (Important to make clear the benefits of their participation, and communicate what the JLA considers to be shared priorities)
4. Some initial desk work to establish the remit of the research funder e.g. size of funding, nature of funding (*the UKCRC UK Health Research Analysis and the Patient View Handbook of Patient Groups could be useful here*)
5. Telephone or face-to-face interviews with the key people (clinicians/researchers/managers and patients/public), in each of the research funding organisations.
6. Synthesis of gathered information and present scope in a final report

7. Project outputs

- A scoping report to the JLA MIG by the 31st March 2008 – detail yet to be agreed, but need to include an executive summary
- A list of key contacts of each of the participating research funders
- A reference list for the rapid appraisal of key papers

8. Costings

We have £20 K to allocate to this work, to VAT, travel and incidental costs.

9. References

¹ UKCRC UK Health Research Analysis, May 2006

² "A bibliography of research reports about patients', clinicians' and researchers' priorities for new research", Oliver S, Gray J available on the JLA website www.lindalliance.org

³ "Using lay reviewers in the peer review process" AMRC Briefing Paper December 2006 available on AMRC website www.amrc.org.uk

⁴ Involving consumers in research and development agenda setting for the NHS: Developing an evidence based approach. Oliver S et al, Vol 8 No 15 2004 available on the HTA Programme website www.hta.nhsweb.nhs.uk

⁵ "Consumer Involvement in decisions about what health related research is funded" O'Donnell M, Entwistle V, Health Policy 70 (2004) 281 – 290

⁶ "Priority Setting approaches for James Lind Alliance (JLA) Working Partnerships" Crowe S, May 2006 available on the JLA website www.lindalliance.org

Next steps for this proposal:

- Send the specification to the sub contractor
- Sub contractor to undertake some preliminary planning work (to be paid for) and report to SC and LF on the 17th September 2007
- Agree sub contracted work, and contract with TwoCan
- Aim to start no later than beginning of October 2007
- Arrange a schedule of meetings and agree communication channels so that TwoCan can keep the JLA up to date with progress and JLA can assist in the project as needed.

Further contact on this specification to be via

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