



**The James Lind Alliance**  
"Tackling treatment uncertainties together"  
[www.lindalliance.org](http://www.lindalliance.org)

**Annual Report**  
**April 2007 – March 2008**

**Summary of key achievements**

- The James Lind Alliance (JLA) has concluded its first Working Partnership (Asthma) **[4.1]** and has commenced its second (Urinary Incontinence), which is due for completion by the end of 2008 **[4.2]**.
- It has submitted a successful Research for Patient Benefit bid in partnership with the Centre for Evidence Based Dermatology, to set priorities and reduce uncertainties in the prevention and treatment of skin disease **[4.3]**.
- The JLA has commissioned a number of studies exploring patients', clinicians' and researchers' priorities for research and the nature of research priority setting in the UK:
  - *Bibliography of research reports about patients', clinicians' and researchers' priorities for new research* (Oliver and Gray) **[5.1.1]**
  - *Research priority setting in the UK* (TwoCan Associates) **[5.1.2]**
  - *A systematic map of studies of patients' and clinicians' research priorities* (Stewart and Oliver) **[5.1.3]**
- Partnerships are central to the JLA way of working. Partnerships have been developed throughout 2007 / 2008 with the Association of Medical Research Charities (AMRC), INVOLVE, invoNET, the UK Clinical Research Collaboration (UKCRC), the UK Clinical Research Network (UKCRN), the National Library for Health (NLH), the Database of Uncertainties about the Effects of Treatments (DUETs), the Health Coalition Initiative and the Patient Information Forum **[6.2]**.
- During the course of the year, the JLA's profile has grown considerably. It has hosted two seminars, produced a number of articles, reports and briefing papers, and has delivered a series of presentations. Its website was visited in excess of 30,000 times and to date over 100 organisations have joined its affiliate programme **[7.1]**.
- The JLA has secured the continued support of its funders for a further two years, to March 2010 **[8.1]**.

## **Annual report**

This interim review sets out the activities and progress of the James Lind Alliance (JLA) from April 2007 to March 2008. It should be read in conjunction with the JLA Performance Tracker 2007-2008 (Annexe 1).

### **1. Background and context**

- 1.1. The James Lind Alliance (JLA) was developed following a decision by the Medical Research Council (MRC) in 2003 to make a commitment to “involve patients (consumers) in all aspects of the clinical trials it funds.” This was set out in the MRC publication, *Clinical Trials for Tomorrow* (Annexe 2).
- 1.2. Initially the James Lind Initiative (JLI) was established by Iain Chalmers and Patricia Atkinson. This was funded by the MRC and the Department of Health (DH) to support the delivery of this commitment.
- 1.3. After wide consultation it was decided to pursue a strategy encouraging wider recognition of uncertainties about the effects of treatments and to examine the responsibilities of health professionals when faced with such uncertainties.
- 1.4. In 2004 the JLA was established as part of the JLI. The founders and co-conveners were Iain Chalmers (JLI), John Scadding (Royal Society of Medicine) and Nick Partridge (INVOLVE).
- 1.5. An influential and broadly based steering group was established. This was chaired by Sally Crowe.
- 1.6. On 1<sup>st</sup> April 2007 a three year funding programme was agreed by MRC and DH, subject to an interim review on 31<sup>st</sup> March 2008.

### **2. Resource and capacity**

- 2.1. The JLA is led at a strategic level by the Strategy and Development Group (SDG), which is now chaired by Lester Firkins. This meets three to four times per year. A list of current members is at Annexe 3.
- 2.2. The JLA is managed via the Monitoring and Implementation Group (MIG), chaired by Sally Crowe (Annexe 4). This meets monthly.
- 2.3. The secretariat activities are undertaken by Patricia Atkinson (as part of her JLI-funded role). Sally Crowe, Lester Firkins and Katherine Cowan (an independent consultant appointed in response to a growing workload) undertake day to day activities on a part time consultancy basis supported by members of the SDG and MIG as required.

### **3. Relevance within health**

- 3.1. The JLA ethos of involving patients and clinicians in the priority setting process for treatment uncertainties fits comfortably within the evolving health research and development agenda.
- 3.2. The identification of and approach to treatment uncertainties and research outcomes of interest to patients and carers has become more integral to research and development since the inception of JLA, as demonstrated by the following initiatives:
  - 3.2.1. The Research for Patient Benefit programme of the National Institute for Health Research, which supports projects in Health Services Research and Public Health aiming to assess developments in healthcare which will benefit patients (Annexe 5).
  - 3.2.2. Patient and Public Involvement (PPI) strategies for the UK Clinical Research Network (UKCRN) and UK Clinical Research Collaboration (UKCRC), which both aim to help patients contribute to the development of clinical research and areas of interest to patients (Annexe 6 and Annexe 7).
  - 3.2.3. The Cooksey review of health research funding, which makes recommendations around establishing and communicating the UK's health research priorities (Annexe 8).

### **4. Developing methods to deliver shared prioritised treatment uncertainties**

- 4.1. The first JLA Working Partnership (Asthma) has now concluded and the methods, outcomes and learning have been documented as follows:
  - 4.1.1. Detailed methods articles and a comment paper (with encouragement from the British Medical Journal) are being drafted.
  - 4.1.2. The report of the priority setting workshop is on the JLA website (Annexe 9).
  - 4.1.3. An external observational report of the priority setting workshop is also on the JLA website (Annexe 10).
- 4.2. The second Working Partnership (Urinary Incontinence) commenced in 2007 with conclusion planned for the end of 2008. The following documents have been produced, which can also be found on the JLA website:
  - 4.2.1. The Urinary Incontinence/JLA protocol (Annexe 11).
  - 4.2.2. Reports of public Working Partnership meetings on 23<sup>rd</sup> May 2007 and 18<sup>th</sup> March 2008. (Annexe 12 and Annexe 13).
  - 4.2.3. Articles and journal publications (Annexe 14).
- 4.3. A successful Research for Patient Benefit bid has been submitted, in partnership with the Centre for Evidence Based Dermatology (Annexe

## 5. Establishing a baseline of evidence for shared research priority setting

5.1. The most recent systematic review of PPI in research priority setting was published in 2004 (*Consumer involvement in decisions about what health related research is funded*, O Donnell and Entwistle, Health Policy 70 281 – 290). Much has changed in the intervening years and the JLA sees the completion of an up-to-date evidence base in this area as needed to inform the way it works. Working Partnerships need to know that the aims, methods and partnerships they pursue are based on shared experiences and results from other research groups. Evidence is required for the methods of establishing shared uncertainties, priority setting and effective partnership making, as well as on how prevalent this type of activity is across the UK.

5.1.1. *Bibliography of research reports about patients', clinicians' and researchers' priorities for new research* (Oliver and Gray) was commissioned by the JLA and is available on the website (Annexe 16).

5.1.2. *Research priority setting in the UK* (TwoCan Associates) has been commissioned by the JLA and is in course of completion. The aim of this project is to carry out a preliminary scoping exercise to find out how clinical research bodies set their priorities and whether and how patients and the public are involved in this work. This will help JLA to make informed decisions about how best to work with research funders and know when they can add value to decision-making. It will also help to identify how best to present 'worked up' shared clinical and patient priorities to research funders, and strengthen their relationship with research funders and extend their networks. See Annexe 17 for the tender specification and Annexe 18 for the proposal.

5.1.3. JLA has also commissioned *A systematic map of studies of patients' and clinicians' research priorities* (Stewart and Oliver (2008) – not yet available to view). This work sets out to develop the JLA *Bibliography of research reports about patients', clinicians' and researchers' priorities for new research* by locating full reports of patients' and clinicians' priorities for research. It also hopes to better understand the routes through which patients and clinicians contribute to priorities for research and to reflect on the work of the JLA in relation to this wider literature.

## 6. Partnership working

6.1. The concept of *partnerships* is central to the JLA way of working. This can include collaborative conferences, research, articles and publications, or committee representation.

- 6.2. Key partners during 2007 / 2008 have been:
- 6.2.1. AMRC, the Association of Medical Research Charities, a membership organisation of the leading medical and health research charities in the UK.
  - 6.2.2. INVOLVE, which promotes and supports active public involvement in NHS, public health and social care research.
  - 6.2.3. invoNET, a specialist network of researchers, clinicians, patients and carers interested in PPI in research.
  - 6.2.4. The UKCRC, a partnership of organisations working to establish the UK as a world leader in clinical research.
  - 6.2.5. The UKCRN, which supports clinical research and facilitates the conduct of trials.
  - 6.2.6. NLH, the National Library for Health, one of the principal components of the NHS's National Knowledge Service.
  - 6.2.7. DUETS, the Database of Uncertainties about the Effects of Treatments. It is one of the NLH's Specialist Libraries (as well as featuring in the work of all the other specialist libraries), established to identify and publish questions about the effects of treatments which cannot be answered by existing up-to-date systematic reviews.
  - 6.2.8. The Health Coalition Initiative, a network of voluntary health organisations and pharmaceutical companies.
  - 6.2.9. Patient Information Forum, an independent organisation that promotes high-quality information for patients, carers and their families.

## 7. Awareness raising

- 7.1. The JLA has taken steps to create increased awareness of the debate around treatment uncertainty and of the need for shared research priorities. Activities during 2007-2008 are listed below.
- 7.1.1. Seminar programme: on 25<sup>th</sup> June 2007 JLA and *The Lancet* jointly hosted *How can clinical trialists serve the needs of clinicians and patients more effectively?*, and on 17<sup>th</sup> September 2007, in partnership with the AMRC, they hosted *Should patients tell researchers what to do? If so, how?* (Annexe 19).
  - 7.1.2. Publications: a number of publications and articles have been produced in a range of journals (Annexe 20).
  - 7.1.3. Presentations: a number of presentations on the JLA were given during the year (Annexe 21).
  - 7.1.4. Website: during the year [www.lindalliance.org](http://www.lindalliance.org) received a total number of 31,730 visits, with an increase of 55 per cent between April 2007 (1949 visits) and March 2008 (3037 visits) (Annexe 22).
  - 7.1.5. Affiliate programme: organisations and individuals who identify strongly with the objectives of the JLA, and wish to be involved, can affiliate to the JLA, and receive periodic progress information. To date, 110 organisations are affiliated, an increase of just over 50 per cent from 73 affiliates the previous year. (Annexe 23).

## 8. Next steps

- 8.1. The funders have agreed to continue support for a further two years (to March 2010)
- 8.2. A revised set of Performance Metrics and Tracker for 2008 – 2009 has been agreed by the SDG.

Lester Firkins  
Chair, Strategy and Development Group

## List of annexes

Annexe	Title
1	JLA Performance Tracker 2007-2008
2	<i>Clinical Trials for Tomorrow</i> , MRC
3	JLA Strategy and Development Group members
4	JLA Monitoring and Implementation Group members
5	Research for Patient Benefit programme
6	UKCRN Patient and Public Involvement Strategic Plan 2006-2008
7	UKCRC Patient and Public Involvement Strategic Plan 2008-2011
8	A review of UK health research funding, Sir David Cooksey
9	JLA workshop to set research priorities in asthma
10	Reflective report on the JLA Asthma Priority Setting Meeting
11	JLA Urinary Incontinence Working Partnership protocol
12	JLA Urinary Incontinence Working Partnership meeting, 23 May 2007
13	JLA Urinary Incontinence Working Partnership meeting, 18 March 2008
14	JLA Urinary Incontinence Working Partnership publications and articles
15	JLA Dermatology Research for Patient Benefit bid
16	<i>Bibliography of research reports about patients', clinicians' and researchers' priorities for new research</i> , Oliver and Gray
17	<i>Research priority setting in the UK</i> , tender specification
18	<i>Research priority setting in the UK</i> , proposal by TwoCan Associates
19	JLA seminar programme
20	JLA publications and articles
21	JLA presentations
22	JLA website statistics
23	JLA affiliates list