



The James Lind Alliance

“Tackling treatment uncertainties together”

www.lindalliance.org

Report

April 2008 – March 2010

Summary of key achievements

- The James Lind Alliance (JLA) has taken two Priority Setting Partnerships to completion: Urinary Incontinence and Vitiligo. Nine further Priority Setting Partnerships were established and are underway, including schizophrenia, type 1 diabetes and prostate cancer. **[3.1-3.11]**
- The JLA has commissioned a number of studies exploring the nature of research priority setting and the involvement of patients and clinicians:
 - *Patients’ Priorities for Research into Epilepsy* **[4.1.1]**
 - *A Systematic Map of Studies of Patients’ and Clinicians’ Research Priorities* **[4.1.2]**
 - *A Web Review of UKCRN Topic Specific Research Networks* **[4.1.3]**
 - *Scoping Research Priority Setting, and the Presence of Patient and Public Involvement, with UK Clinical Research Organisations and Funders* **[4.1.4]**
- The JLA has maintained existing partnerships and established important new ones with a wide range of stakeholder organisations, including the NIHR Health Technology Assessment programme, the Cochrane Collaboration, NIHR Clinical Research Network Coordinating Centre and NHS Evidence Specialist Collections. **[6.1]**
- There has been a significant amount of work undertaken to raise awareness of the JLA. This includes the launch of a quarterly Affiliates Newsletter **[5.1.5]**, a number of co-hosted seminars **[5.1.1]** and media engagement **[5.1.2]**.
- The JLA has been successful in securing funding until 31st March 2013. **[1.3]**

Annual report

This review sets out the activities and progress of the James Lind Alliance (JLA) from April 2008 to March 2010. It should be read in conjunction with the JLA Performance Trackers 2008-2009 (Annexe 1) and 2009-2010 (Annex 2).

1. Background and context

- 1.1. A non-profit UK-based initiative, the JLA is part of the James Lind Initiative, and is funded by the National Institute for Health Research (NIHR) and the Medical Research Council (MRC).
- 1.2. The aim of the JLA is to bring patients and clinicians together to identify and prioritise treatment uncertainties for research. The JLA does this in three main ways, which are covered by this annual report:
 - Facilitating Priority Setting Partnerships (section 3)
 - Commissioning research (section 4)
 - Awareness raising (section 5)
- 1.3. The JLA is funded by the NIHR and the MRC until 31st March 2013.

2. Resource and capacity

- 2.1. The JLA is led at a strategic level by the Strategy and Development Group (SDG), which is chaired by Lester Firkins. This meets three times per year. Minutes of those meetings are on the JLA website at www.lindalliance.org/Internal_Meetings.asp. A list of current members is at Annexe 3.
- 2.2. The JLA is managed through the Monitoring and Implementation Group (MIG), chaired by Sally Crowe. This meets monthly. A list of current members is at Annexe 3.
- 2.3. The JLA Secretariat is administered by Patricia Atkinson (as part of her JLI-funded role). Sally Crowe, Lester Firkins and Katherine Cowan undertake practical day-to-day activities on a consultancy basis, supported by members of the SDG and MIG as required.

3. Facilitating Priority Setting Partnerships (PSPs)

- 3.1. **Urinary Incontinence:** The JLA PSP on Urinary Incontinence was concluded at a workshop in November 2008 and was the second PSP to be completed, following the completion of the Asthma PSP in 2007. The methods, outcomes and learning have been documented as follows:
 - 3.1.1. The report of the final priority setting workshop is on the JLA website (Annexe 5).
 - 3.1.2. A report based on an online evaluation on participants' experiences of the PSP is also on the website (Annexe 6).
 - 3.1.3. The top ten priorities were reviewed by the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) programme. Nearly all

fall within the scope of the HTA programme and eight have been submitted for consideration by the HTA Advisory Panels.

- 3.2. **Skin disease:** With support from NIHR, a project called **Setting Priorities and Uncertainties for People with Skin Disease (SPRUSD)** was established in 2008 at the Centre for Evidence Based Dermatology in Nottingham. The Centre incorporates the Cochrane Skin Group, the UK Dermatology Clinical Trials Network (UKDCTN), the Centre for Evidence Based Dermatology, and NHS Evidence's special collection on skin disorders. SPRUSD has several streams of work, including full funding over five years for two JLA PSPs - for vitiligo and eczema.
- 3.2.1. The Vitiligo PSP gathered treatment uncertainties from patient, clinicians and existing research, and concluded its priority setting exercise in March 2010. Articles describing the process and results are available on the JLA website:
- 3.2.1.1. *SPRUSD: Research priority for 2009: An opportunity for members to be involved* by Sally Crowe, published in Dispatches issue 49, November 2008 (Page 13). (Annexe 7)
- 3.2.1.2. *Setting priorities and reducing uncertainties for people with skin disease (SPRUSD)* by Clare Lushey, published in Dispatches issue 50, March 2009 (Page 14). (Annexe 8)
- 3.2.1.3. *Have your say in defining the future of vitiligo research*, Dispatches issue 51, July 2009 (Page 16). (Annexe 9)
- 3.2.2. The Eczema PSP will begin in mid-2010.
- 3.3. **Prostate Cancer:** In 2009 the Prostate Cancer Research Foundation and the Prostate Cancer Support Federation, supported by the Prostate Cancer Charter for Action, asked for JLA help to establish a Prostate Cancer PSP, and a meeting was held to raise awareness of the initiative. A survey to gather treatment uncertainties was completed in 2009 and an interim priority setting exercise took place in March 2010. The final priority setting workshop is scheduled for autumn 2010.
- 3.4. **Schizophrenia:** In 2009 a steering group was formed to lead a Schizophrenia PSP, including the universities of Swansea and Nottingham, Rethink, Hafal and the Institute of Psychiatry. A UK DUETs module of schizophrenia treatment uncertainties had already been established through consultation with patients and clinicians organised by the University of Swansea and funded by the Welsh Office of Research and Development. The Schizophrenia PSP is expected to prioritise those uncertainties in 2010.
- 3.5. **Type 1 Diabetes:** A Type 1 Diabetes PSP was established following a workshop in June 2009, with funding from the Insulin Dependent Diabetes Trust. The steering group includes representation from the Diabetes Research Network, Diabetes UK, the Insulin Dependent Diabetes Trust, Juvenile Diabetes Research Foundation, NHS Evidence – diabetes, and the Scottish Diabetes Research Network. An online survey to gather treatment uncertainties was launched in March 2010. Interim and final priority setting will take place later in 2010.
- 3.6. **Ear, Nose and Throat - Aspects of Balance:** This PSP is led by the British Association of Otorhinolaryngologists (part of ENT-UK). Aspects of balance were selected as an initial health problem within the ENT speciality, with a view to extending consideration to other conditions within the speciality if experience with an

aspects of balance PSP is successful. A Steering Group has been established and an awareness meeting for the wider community will be held in May 2010.

- 3.7. **Life after Stroke in Scotland:** This PSP emerged from a project funded by the Scottish Government's National Advisory Committee for Stroke. DORIS (Database of Research in Stroke) has been awarded three-year funding to facilitate a comprehensive database of evidence and priorities specific to stroke rehabilitation within Scotland. DORIS has asked the JLA to help it identify treatment uncertainties, evidence gaps and research priorities. A steering group has been established and a protocol agreed. Awareness raising and harvesting of uncertainties will commence in Autumn 2010.
- 3.8. **Pressure ulcers:** This PSP is at an early stage, with a draft protocol being circulated to potential partners. It will be led by a collaborative research group based at York University with the Cochrane Wounds Group, as part of a wider wounds-related NIHR Programme Grant.
- 3.9. **Bradford NHS Foundation Trust:** This potential PSP aims to identify public priorities for patient safety across the Trust, using multiple methods coordinated by a collaborative group led by the Trust. A proposal has been submitted to the NIHR Service Delivery and Organisation funding programme.
- 3.10. **Epilepsy:** With funding support from the Welsh Office for Research and Development, the Wales Epilepsy Research Network has identified patients' and clinicians' uncertainties about treatments for epilepsy, and these are being entered in the UK Database of Uncertainties about the Effects of Treatments (UK DUETs). Once this work has been completed and further resources obtained, the Network wishes to work with the JLA to establish a JLA PSP.

4. Commissioning research

- 4.1. During 2008/09, the JLA continued to commission and publish research on research priority setting, and the involvement of patients and clinicians in that process.
 - 4.1.1. The JLA and UK DUETs, in collaboration with the University of Wales Swansea and the University Hospital of Wales, commissioned PatientView to carry out a survey of epilepsy patient groups to identify which epilepsy patients' and carers' questions about treatment cannot currently be answered. Thirty five patient organisations took part in the survey (a report is on the JLA website) and the results will be added to UK DUETs. A full report, *Patients' Priorities for Research into Epilepsy*, is at Annexe 10.
 - 4.1.2. The JLA funded Dr Sandy Oliver, Social Science Research Unit (SSRU), to examine the evidence base on user involvement in shared research priority setting. Building on existing bibliographies of user-involvement in setting research agendas, Dr Oliver systematically reviewed abstracts of 258 reports of priority setting exercises involving service users and clinicians to assess how patients and clinicians had contributed to research prioritisation (references for these studies are available on the UK DUETs website - www.library.nhs.uk/duets). The review, *A Systematic Map of Studies of Patients' and Clinicians' Research Priorities*, showed that clinicians were more likely to be involved than patients in priority setting processes, and that clinicians and patients were more likely to work separately than collaboratively.

Dr Oliver found only nine accounts of clinicians and patients working together to identify and prioritise research questions, which suggests that JLA PSPs are highly distinctive. (Annexe 11)

- 4.1.3. Although the NIHR Clinical Research Network does not itself fund clinical research, it does influence the nature and scope of clinical research in the UK, and its Clinical Studies Advisory Groups provide the main route through which new clinical research ideas are developed. The JLA wished to assess how the Topic-Specific Research Networks developed their research ideas, set priorities for their respective clinical research programmes and the extent to which patients and the public are involved in this work. Accordingly, in *A Web Review of UKCRN Topic Specific Research Networks*, the JLA reviewed the websites of UKCRN Topic-Specific Research Networks to assess whether and how they are using formal methods for prioritizing clinical trials, and to assess how priorities emerging from JLA PSPs might be taken into account by the Research Networks and their Clinical Studies Advisory Groups. (Annexe 12)
- 4.1.4. The JLA commissioned a scoping study to find out whether and how clinical research organisations currently set research priorities and whether and how patients and the public are involved in this work. Given the growing profile of the public and patient involvement agenda, the JLA was interested to see if this stated commitment was being reflected in practice. A report entitled *Scoping Research Priority Setting, and the Presence of Patient and Public Involvement, with UK Clinical Research Organisations and Funders* was researched and written by Bec Hanley and Kristina Staley of TwoCan Associates. A summary of the report is at Appendix 13.

5. Awareness raising

5.1. The JLA has worked to increase awareness of the importance of acknowledging treatment uncertainties and identifying those regarded as importance by patients and clinicians. Activities during 2008-2010 are listed below.

5.1.1. Seminar programme:

- 5.1.1.1. In November 2008, the JLA co-hosted with the Social Science Research Unit and the Royal College of Nursing Institute a conference entitled *Outcomes in clinical research – whose responsibility?* It aimed to promote debate about the role of patients, clinicians and researchers in selecting important outcomes to be measured in clinical research, and to go beyond Patient-Reported Outcomes to ensure Patient- Important Outcomes. The conference was attended by over 140 people, including patients, clinicians and researchers. Slide presentations are available on the JLA website and a full report of the event is at Annexe 14.
- 5.1.1.2. In October 2009 the JLA, the Association of Medical Research Charities (AMRC) and National Voices co-hosted a ‘brainstorming’ event attended by 30 invited participants to explore the extent to which the research agenda of the pharmaceutical industry can be influenced by patients and their representative organisations. The JLA has not worked with industry, and the event provided an opportunity to consider how such collaboration might promote research priorities identified by JLA PSPs. A report of the meeting will be published on the JLA website in 2010.

- 5.1.1.3. In February 2010 the JLA, INVOLVE and the AMRC co-hosted a conference entitled *Building on success – opportunities to progress patient and public involvement in research prioritisation and commissioning*. Funds were set aside for this work at earlier UKCRC Patient and Public Involvement Board Subgroup meetings at which it was agreed to consider together the results of related work (JLA's priority setting mapping, INVOLVE's commissioners survey, and the AMRC's Natural Ground Project). The purpose of this event was to see whether, based on the evidence resulting from this work, agreement could be reached on a number of actions to improve both the processes and impact of patient and public involvement in research prioritisation and commissioning. Over 30 senior people from the healthcare research and commissioning sectors attended by invitation only. A programme of the day is at Annexe 15. The event report will be published on the JLA website in 2010.
- 5.1.2. Publications: 10 publications have been produced in a range of journals (Annexe 16).
- 5.1.3. Presentations: 19 presentations on the JLA were given during the two years covered by this report (Annexe 17).
- 5.1.4. Website: during 2008/9 www.lindalliance.org received nearly 40,000 visits, an increase of 24 per cent on the previous year. In 2009/10, the website was visited nearly 50,000 times, an increase of 21 per cent on 2008/9. The final month's total, for March 2010, was 5529 visits – an increase of 47 per cent from the total visits received in April 2008. A Wikipedia page was developed which has increased the profile of the JLA in Google searches (http://en.wikipedia.org/wiki/James_Lind_Alliance).
- 5.1.5. Affiliate programme: organisations and individuals who identify with the objectives of the JLA and wish to be kept apprised of progress and opportunities can become JLA Affiliates. In January 2009, the JLA produced the first of its quarterly newsletters for Affiliates (see Annexes 18-22 for the January, April, July and October 2009 editions and the January 2010 edition). To date, 190 organisations and individuals are Affiliates, an increase of 19 per cent from 2007/2008. (Annexe 23)
- 5.1.6. JLA Guidebook: throughout 2008/2010 the JLA has been producing evidence-based guidance on working with patients and clinicians to identify and prioritise treatment uncertainties. The Guidebook will also include the JLA Protocol, which organisations wishing to form a JLA PSP will sign up to.

6. Partnership working

- 6.1. The concept of *partnership* 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 2008/10 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. The NIHR Health Technology Assessment programme, which produces independent research information about the effectiveness, costs and broader

impact of healthcare treatments and tests for those who plan, provide or receive care in the NHS.

- 6.2.3. The Cochrane Collaboration, the UK Cochrane Centre, which prepare, maintain and disseminate systematic reviews of healthcare interventions
- 6.2.4. INVOLVE, which promotes and supports active public involvement in NHS, public health and social care research.
- 6.2.5. invoNET, a specialist network of researchers, clinicians, patients and carers interested in PPI in research.
- 6.2.6. The UKCRC, a partnership of organisations working to establish the UK as a world leader in clinical research.
- 6.2.7. NIHR CRN CC, the National Institute for Health Research Clinical Research Network Coordinating Centre (formerly UKCRN), which supports clinical research and facilitates the conduct of trials and Topic Specific Research Networks. The JLA works with the PPI network and individual Clinical Studies Advisory Groups, such as diabetes.
- 6.2.8. NHS Evidence, Specialist collections - Evidence in Health and Social Care.
- 6.2.9. PatientView, a research and publishing organisation that works with patients and health and social campaigning groups.
- 6.2.10. UK Duets, the UK Database of Uncertainties about the Effects of Treatments. It is part of NHS Evidence and a crucial part of the priority setting process.
- 6.2.11. National Voices, a coalition of more than 200 national health and social care organisations promoting a stronger voice for all those who come into contact with NHS and care services, and the voluntary organisations that help them.
- 6.2.12. The JLA is also represented on a number of committees including the Cochrane Priority Setting Methods Group, the UK Reviews Infrastructure Advisory Board, the NIHR CRN Consultative Panel *The way forward for better research with patients and public*, the UK DUETs Advisory Board, the Database of Research in Scotland Advisory Board, the NIHR Dermatology Programme Grant Award Steering Committee, the UKCRC Clinical Research Funders Group and the NIHR CRN Wider Forum Group.

7. Next steps

- 7.1. Following a successful proposal to NIHR and MRC from the JLA to retain its funding stream, the funders have agreed to continue support to March 2013.
- 7.2. A set of Performance Metrics and Tracker for 2010-2011 has been established (Annex 24)

Lester Firkins

Chair, Strategy and Development Group

List of annexes

Annexe	Title
1	JLA Performance Tracker 2008-2009
2	JLA Performance Tracker 2009-2010
3	SDG Members List
4	MIG Members List
5	Urinary Incontinence Priority Setting Partnership final report
6	Urinary Incontinence Priority Setting Partnership evaluation
7	Vitiligo Priority Setting Partnership Dispatches article, issue 49
8	Vitiligo Priority Setting Partnership Dispatches article, issue 50
9	Vitiligo Priority Setting Partnership Dispatches article, issue 51
10	Patients' Priorities for Research into Epilepsy, PatientView report
11	Systematic Map of Studies of Research Priorities, SSRU report
12	Topic Specific Research Networks web review
13	Scoping Research Priority Setting, TwoCan summary report
14	Outcomes in Clinical Research conference report
15	Building on Success, event programme
16	JLA Publications List
17	JLA Presentations List
18	JLA Affiliates Newsletter January 2009
19	JLA Affiliates Newsletter April 2009
20	JLA Affiliates Newsletter July 2009
21	JLA Affiliates Newsletter October 2009
22	JLA Affiliates Newsletter January 2010
23	JLA Affiliates List
24	JLA Performance Metrics and Tracker 2010-2011