



## Affiliates Newsletter – April 2009

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### MESSAGE FROM THE CHAIR

Dear Colleague,

Welcome to our second Affiliates Newsletter of 2009.

We are currently in the process of finalising our Business Plan for our third year to March 2010 – and I am delighted to report that we are extremely busy in many positive areas – as this newsletter will show.

The Priority Setting Partnerships are our life-blood, the heart of the process whereby patients and clinicians work together to agree on priorities in treatment uncertainty research. We are just about to start a new initiative with prostate cancer. This very challenging and increasingly high profile condition will be a strong test of our processes. We look forward to it!

The JLA continues to be seen as a valuable and important resource, not least by our partners and our funders. Kay Pattison, National Institute for Health Research (NIHR) Programme Manager at the Department of Health, recently noted that “the collaboration between the James Lind Alliance and the Urinary Incontinence Cochrane Review Group was described in extremely positive terms by both parties. I would encourage other groups considering collaboration to make the necessary links.”

We hope you'll find this Newsletter interesting and informative – as always, we welcome your comments and feedback.

Thank you so much for your continued support,

Lester Firkins, Chair, James Lind Alliance

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## NEWS

### A 'how to' guide to the JLA

The JLA process of involving patients and clinicians in identifying priorities for research is thought to be unique. We are therefore keen to ensure the lessons we learn and the good practice developed by our Priority Setting Partnerships are captured and shared widely.



Over the coming year, the JLA will be developing a step-by-step, evidence-based Guidebook to developing a Priority Setting Partnership, including harvesting and shortlisting treatment uncertainties and agreeing a top 10 list of priorities for research, as well as managing the challenges which come with a priority setting process.

It is anticipated that the Guidebook will primarily be an online resource which can be updated as new evidence and good practice emerge. It will be user-friendly and will encourage and enable other groups to form partnerships between clinicians, patients and carers and prioritise their shared research priorities, in order to influence the research agenda. It will also give other known examples of research priority setting work, and evidence of the benefits of involving patients and carers in that process, to support the premise of a Priority Setting Partnership.

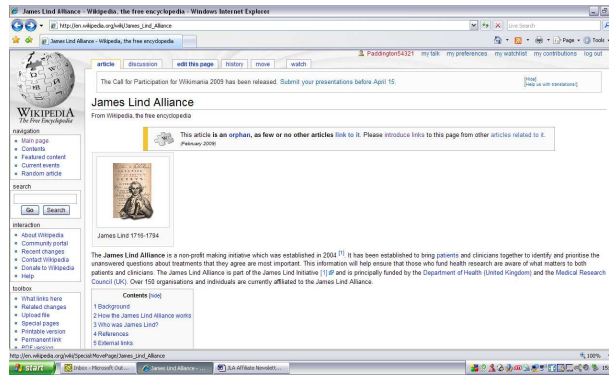
The development of the Guidebook is being overseen by the JLA's Strategy & Development Group, and the Monitoring & Implementation Group. An independent Critical Friends Group has also been established to advise on the development of the Guidebook. Members include representatives of both patient and clinician groups and will ensure non-JLA views and the perspectives of potential users and beneficiaries of the final product are taken into account.

This project is being managed by Katherine Cowan. For further information please contact [katherine@katherinecowan.net](mailto:katherine@katherinecowan.net).

## JLA on Wikipedia



Affiliates Newsletter – April 2009



In addition to the new-look JLA website ([www.lindalliance.org](http://www.lindalliance.org)), we are now also featured on Wikipedia, the free online encyclopaedia. You can support us and increase the profile of our work by mentioning your affiliation to the JLA on your own Wikipedia entry, and adding an internal link to our page.  
[http://en.wikipedia.org/wiki/James\\_Lind\\_Alliance](http://en.wikipedia.org/wiki/James_Lind_Alliance).



The UK Database of Uncertainties about the Effects of Treatment (DUETs) is now firmly established as part of the National Library for Health (NLH) at [www.library.nhs.uk/duets](http://www.library.nhs.uk/duets). This change into the NLH is to widen participation from the Specialist Libraries in the harvesting of uncertainties as part of their Annual Evidence Updates. Most of the condition-based Specialist Libraries within the NLH are now required to identify and record treatment uncertainties as part of the Annual Evidence Updates they undertake on many health conditions. From the end of April this work will be incorporated in NHS Evidence.

### New Year's Honours

Congratulations to Nick Partridge, member of the JLA Strategy & Development Group, whose 20 years of service to healthcare was recognised with a Knighthood in the 2009 New Year Honours List. Nick is Chief Executive of the Terrence Higgins Trust and Chair of INVOLVE, the advisory group promoting public involvement in NHS, public health and social care research.

The JLA Strategy & Development Group is now proud to boast two Knights of the Realm: Sir Nick and Sir Iain Chalmers, from the James Lind Library, both of whom were founders of the JLA.

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### PARTNERSHIPS UPDATE



The JLA Priority Setting Partnerships (formerly known as Working Partnerships) are comprised of patients, carers and clinicians, working together to identify treatment uncertainties, and to prioritise uncertainties for research. Groups or consortia interested in forming a JLA Priority Setting Partnership should initially contact Patricia Atkinson ([patkinson@lindalliance.org](mailto:patkinson@lindalliance.org)).

### Urinary Incontinence

The Urinary Incontinence Priority Setting Partnership interim report is now available on our website. The report documents the activities undertaken during the final priority setting workshop which took place at the end of 2008. Of the final top ten priorities (which will be published in a forthcoming publication) five were originally submitted by clinicians, four by patients and one came from recommendations in a Cochrane Review. A huge amount of work went into bringing this Partnership to fruition and the JLA is very grateful for the efforts and commitment of the individuals involved.



Final priority setting meeting, November 2008

[www.lindalliance.org/UI\\_Working\\_Partnership.asp](http://www.lindalliance.org/UI_Working_Partnership.asp)

### Vitiligo and Eczema

Priority Setting Partnerships for two skin conditions are being established as part of a project commissioned by the National Institute for Health Research (Research for Patient Benefit) under the Programme Grants for Applied Research, called **Setting Priorities and Uncertainties for People with Skin Disease (SPRUSD)**. Vitiligo affects about one per cent of the world's population, and is a condition in which patches of skin lack pigmentation. Eczema affects one in nine of the population and a recent paper in the *Journal of the Royal Society of Medicine* suggests that the number of cases has been rising dramatically. The JLA Priority Setting Partnerships for these important conditions is being co-ordinated by the Centre for Evidence Based Dermatology in Nottingham, which incorporates the NLH Skin Disorders Specialist Library, the Cochrane Skin Group and the UK Dermatology Clinical Trials Network.

The first vitiligo meeting takes place in April, with final priority setting activity planned for December. It is anticipated that the inaugural eczema meeting will take place towards the end of 2009. For further information please contact Sally Crowe ([sally@crowe-](mailto:sally@crowe-)

[associates.co.uk](http://associates.co.uk)). All documentation relating to these Priority Setting Partnerships is on our website ([www.lindalliance.org/Vitiligo\\_Priority\\_Setting\\_Partnership.asp](http://www.lindalliance.org/Vitiligo_Priority_Setting_Partnership.asp)).

### **Prostate Cancer**

The JLA has been asked to develop and manage a Priority Setting Partnership for interested patient and clinician organisations within prostate cancer.

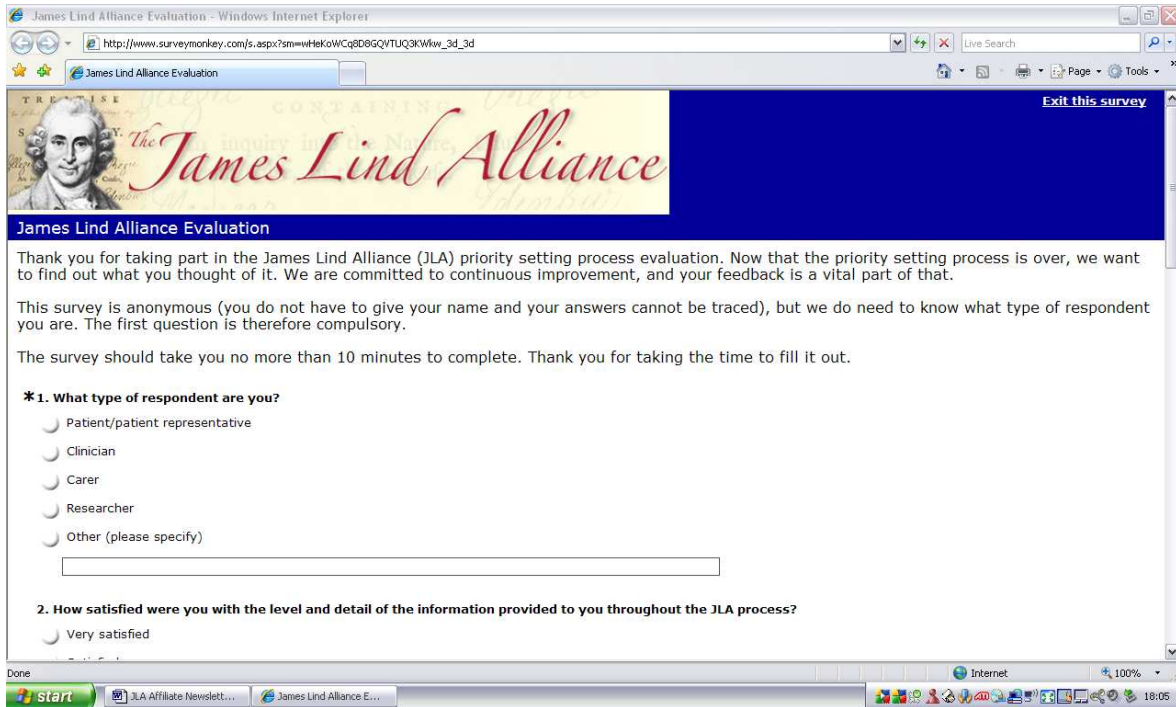
Although the initial approach came from the Prostate Cancer Research Foundation and the Prostate Cancer Support Federation, supported by the Prostate Cancer Charter for Action, the initiative is open to any patient or clinician organisations with an interest in helping to harvest and then prioritise treatment uncertainties in prostate cancer. An initial stakeholder meeting is planned for 10 June 2009. If your organisation would like to attend and hear more about our plans for the Partnership please let us know. For further information, please contact Lester Firkins ([lesterfirkins@mac.com](mailto:lesterfirkins@mac.com)).

### **Type 1 Diabetes**

The JLA Diabetes Priority Setting Partnership has decided to concentrate specifically on Type 1 diabetes. This usually starts in childhood or young adulthood and is caused by a severe lack of insulin, because most of the cells that produce it in the pancreas have been destroyed. It can be life-threatening, but currently no cure exists. A workshop involving a range of interested parties, including the Juvenile Diabetes Research Foundation, NIHR Diabetes Research Network and the Insulin Dependant Diabetes Trust, will take place in June. Please contact Patricia Atkinson ([patkinson@lindalliance.org](mailto:patkinson@lindalliance.org)) for further information.

### **Improving our partnership working**

On completion of the Urinary Incontinence Priority Setting Partnership, the JLA asked participants to feed back their views on the process, through an anonymous online survey. This was an opportunity to identify strengths and weaknesses in the process, from a partner perspective. Data captured by the survey will be used by the JLA to inform, develop and improve future partnerships.



Overall, the feedback was very positive: the majority of respondents were happy with the practical support provided by the JLA, such as meetings, communication and information provision, and most were satisfied with the interim and final priority setting processes themselves. In future, as a result of our partners' suggestions, the JLA will consider limiting to 20 the interim priorities the partners are asked to identify, to ensure the task is completed and not too overwhelming. We will also ensure partners nominate a deputy to ensure balanced attendance between patients and clinicians at the final priority setting meeting.

The box below has a selection of comments about the JLA priority setting process:

*Certainly I as a researcher will use this information to inform what projects we take forward in future.*

*It has helped to clarify research uncertainties, and hopefully it will give incontinence research some credence and standing. Too often, funding is hard to come by because incontinence is considered not to be very sexy.*

*I think it is a very valuable way of encouraging an interchange of views which does not usually happen between clinicians, researchers and patients. It has reaffirmed my views of the need to involve patients much more in such work.*

The full evaluation, including recommendations, is available to download from our website: [www.lindalliance.org/UI Working Partnership.asp](http://www.lindalliance.org/UI_Working_Partnership.asp).



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## RESEARCH

The JLA is working to develop a body of research to inform patient involvement in research priority-setting. If you are involved in or aware of similar research in this field, do let us know by contacting the JLA office.

### **Patients' and clinicians' research priorities**

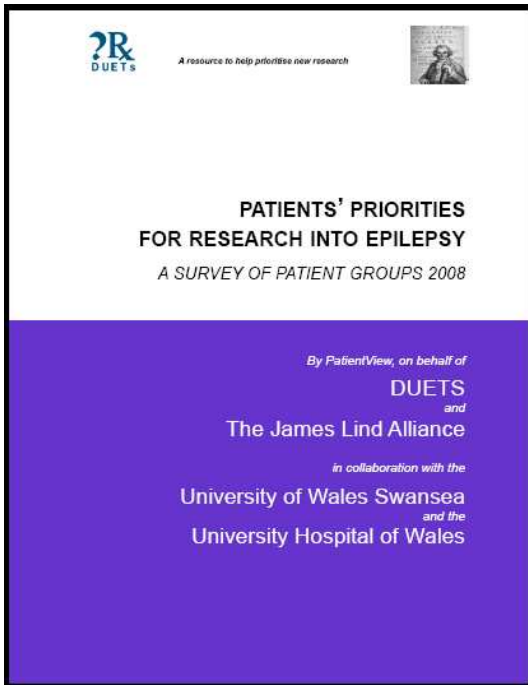
This work built on a previous JLA *Bibliography of research reports about patients', clinicians' and researchers' priorities for new research* ([www.lindalliance.org/Publications.asp](http://www.lindalliance.org/Publications.asp)) by locating full reports of patients' and clinicians' priorities for research. This enabled the JLA to better understand the routes through which patients and clinicians contribute to priorities for research.

The research identified 258 studies addressing research priorities, which revealed the variety of different ways in which clinicians and patients have contributed to research priorities. References for these studies are available on the DUETs website ([www.library.nhs.uk/duets](http://www.library.nhs.uk/duets)). The focus of patients' and clinicians' contributions has varied from general topics to specific research questions. These cover a wide range of health topics, but work in cancer and mental health dominate. Clinicians are more likely to be involved than patients in the process, and clinicians and patients are more likely to work separately than collaboratively. With only nine other accounts of clinicians and patients working together to identify and prioritise research questions, the JLA Priority Setting Partnerships appear highly distinctive. More detail will follow in the next Newsletter.

### **Patients' priorities for research into epilepsy**

In 2008, an online survey of relevant patient organisations was undertaken by PatientView, on behalf of DUETs and the JLA in collaboration with the University of Wales Swansea and the University Hospital of Wales, to identify the questions that epilepsy patients have about their treatment which their doctors cannot currently answer. The uncertainties identified through this survey, together with others that emerged through some very important research done under the aegis of the Welsh Epilepsy Research Network, are being prepared for publication in DUETs.





[www.lindalliance.org/Patients\\_priorities\\_for\\_research\\_in\\_Epilepsy.asp](http://www.lindalliance.org/Patients_priorities_for_research_in_Epilepsy.asp).

### **Web review of Topic Specific Research Networks**

The JLA is keen to examine other groups that adopt formal priority setting in research funding and commissioning, both in terms of what the JLA can learn, but also to identify how priorities that emerge from JLA Priority Setting Partnerships can be integrated into research funding models. Whilst the National Institute for Health Research Clinical Research Network (NIHR CRN - formerly the UK Clinical Research Network) is not a funder of clinical research, it does influence and support the nature and scope of clinical research in the UK. Its Clinical Studies Groups provide the primary route through which new clinical research ideas are developed. The JLA was interested in how the Topic Specific Research Networks developed their research ideas and set priorities for their respective clinical research programmes, and the extent to which patients and the public are involved in this work. A web review of the Topic Specific Research Networks was undertaken in parallel with other larger scoping projects [www.lindalliance.org/UKCRN\\_Web\\_Review.asp](http://www.lindalliance.org/UKCRN_Web_Review.asp).

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### **RECENT EVENTS**



Affiliates Newsletter – April 2009

Lester Firkins spoke at the **14<sup>th</sup> Annual Meeting of UK and Ireland-based Contributors to the Cochrane Collaboration** in Edinburgh in March. The organisers remarked: "Lester gave a stimulating and, at times, poignant presentation of a model for involving key consumer stakeholders in prioritising clinical research into important uncertainties of treatment effects. It is now up to the rest of us to take up his offer of collaborative working to tackle the many uncertainties that really matter and prioritise our clinical research accordingly."



In addition, the JLA also participated in the following events during March:

- Keynote Presentation - Patient Information Forum
- Wellcome Trust Edinburgh Clinical Research Facility Open Day
- Nurses and Allied Health in Critical Care, Edinburgh

Slides and audio commentary for Lester Firkins' presentation to the Cochrane Group in Baltimore are now online at: [www.slideshare.net/Cochrane.Collaboration/the-james-lind-alliance-and-i-presentation](http://www.slideshare.net/Cochrane.Collaboration/the-james-lind-alliance-and-i-presentation)

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## FORTHCOMING EVENTS

The JLA is looking forward to being involved in the following events in 2009:

### JLA and AMRC joint event

Jointly with the Association of Medical Research Charities (AMRC), the JLA will be hosting a 'think-tank' style workshop to explore the extent to which the research agenda of the pharmaceutical industry is or can be influenced by patient priorities. This half-day, central London event, to be held in the autumn, will be chaired by Simon Denegri, Chief Executive of the AMRC, and will involve invited guests from across the relevant sectors.

If you would like the JLA to participate in **your event**, let us know. We can then promote the event in the Newsletter.

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## ON THE WEB



The papers, presentations and a report from the JLA's November conference, **Outcomes in clinical research – whose responsibility?**, are now on our website. Discussion sessions covered 12 topics, including children's outcomes in research, back pain, mental health, pregnancy and childbirth, and multiple sclerosis.  
[www.lindalliance.org/JLA\\_SSRU\\_RCNI\\_Outcomes\\_Conference\\_Nov\\_2008.asp](http://www.lindalliance.org/JLA_SSRU_RCNI_Outcomes_Conference_Nov_2008.asp)

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## CURRENT AFFILIATES

The JLA currently has 173 Affiliates, most of which are listed on our website, with links to their websites. Affiliation is a simple, cost-free way for individuals and organisations to demonstrate support for the JLA's aims, and to remain up-to-date, informed and involved in our activities.

Among our newest Affiliates are Dr Helen Cheyne from the Nursing, Midwifery and Allied Health Professions (NMAHP) Research Unit based at the University of Stirling, and Professor Christine McCourt, from Thames Valley University London, who is currently visiting professor at the NMAHP Unit. They have recently launched the Mothers in Research Agenda Setting (MIRAS) project. The aim is to work with maternity care service users to identify and develop a set of potential topics for research relevant to maternity care in Scotland, to investigate these further, then to draw up a list of agreed priorities. For further information please contact [christine.mccourt@stir.ac.uk](mailto:christine.mccourt@stir.ac.uk).



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## WANT TO FIND OUT MORE?

If you are new to the JLA or simply want to find out more about Patient and Public Involvement in research priority setting, please visit our website: [www.lindalliance.org](http://www.lindalliance.org).

In the Publications section you will find a comprehensive bibliography, along with an archive of JLA publications, to download.

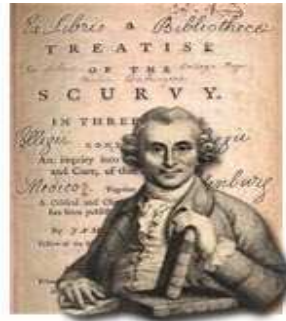
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## KEEP IN TOUCH!

We hope you have enjoyed the latest JLA Affiliates' Newsletter. Please contact us with any news, feedback, updates or information you would like to see featured in the next edition, in July.

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