



**Affiliates Newsletter – July 2009**

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**MESSAGE FROM THE CHAIR**

Dear Colleague,

Welcome to the third Affiliates Newsletter of 2009. We have much to report, and we hope that you will find something of interest within the Newsletter for you and, where appropriate, your organisation.

The James Lind Alliance is becoming increasingly well-known for our work with Priority Setting Partnerships, but we are also working to develop robust research and evidence to inform what we do. This issue of our Newsletter includes a summary of important research looking at how patients are involved in priority setting decisions made by research funding bodies.

The JLA seems to have reached a “tipping point” in its evolution: an increasing number of groups are now approaching us to discuss how they can tackle prioritisation of treatment uncertainties. This variety is rewarding on a personal level as well as providing us with opportunities to work within different organisational structures. As a result, the body of evidence on different ways in which priority setting can work continues to grow.

We hope you’ll find this Newsletter informative. As always, we welcome your comments and feedback.

Thank you for your continued support,

Lester Firkins, Chair, James Lind Alliance

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## NEWS

### Health Technology Assessment programme



The eventual funding of research priorities is integral to the JLA's purpose, so we are delighted that the JLA process of identifying patients' and clinicians' priorities has been singled out by the HTA in its Annual Report.

The report notes that the HTA programme has been working with the JLA to help with the development of the UK Database of Uncertainties about the Effects of Treatments (UK DUETs), with the aim of this becoming another source of research topics which can be taken forward through its established commissioned funding route. The HTA has been working with the JLA to ensure that "any uncertainties identified and prioritised through Priority Setting Partnerships of patients and clinicians, that may be suitable, are referred to the programme". Priorities identified by the first partnerships on asthma and urinary incontinence are currently being developed further and suitable topics will be taken forward by the programme. This is great news for current and future Priority Setting Partnerships, who can be assured that the hard work required to make a partnership work is being recognised and supported by a body which may then fund the research required to turn prioritised uncertainties into knowledge, if not certainties.



### Launch of Clinical Trials, a new section on [www.healthtalkonline.org](http://www.healthtalkonline.org)

On 23 June, Jon Snow, patron of the DIPEX Charity, chaired the launch of a new section of the award-winning website [www.healthtalkonline.org](http://www.healthtalkonline.org), about people's experiences of clinical trials. Speakers included Professor Dame Sally Davies, Director General for Research and Development, Department of Health; Sir Iain Chalmers, Editor of the James Lind Library; Sir David Weatherall, Emeritus Regius Professor of Medicine, University of Oxford; and Lester Firkins, Chair of the JLA.



Lester Firkins, JLA Chair

Based on research led by the DIPEX Health Experiences Research Group at the University of Oxford, the new section presents video and audio interviews with over 40 people talking about why they took part – or chose not to take part – in a clinical trial, what information they needed and what it was like for them. The research was funded by the National Institute for Health Research, and will provide a valuable resource for patients thinking about taking part in trials, as well as for professional training. Visit this exciting and innovative resource at [www.healthtalkonline.org/medical\\_research/clinical\\_trials](http://www.healthtalkonline.org/medical_research/clinical_trials).





## DUETS NHS Evidence Health Information Resources

On 30 April 2009, the National Library for Health transferred to NHS Evidence Health Information Resources and can be found at [www.library.nhs.uk](http://www.library.nhs.uk). NHS Evidence incorporates some of the key components from the National Library for Health, including the UK Database of Uncertainties about the Effects of Treatments (UK DUETs). UK DUETs is a key element of the JLA process, and organisations wanting to enter into a Priority Setting Partnership must commit to ensuring all the treatment uncertainties they gather as part of the process are verified and entered into UK DUETs before priority setting commences. [www.library.nhs.uk/DUETs](http://www.library.nhs.uk/DUETs)

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### PARTNERSHIPS UPDATE

The JLA Priority Setting Partnerships are comprised of patients, carers and clinicians, working together to identify treatment uncertainties and to prioritise uncertainties for research. Individuals, 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 report of the Urinary Incontinence Priority Setting Partnership final priority setting meeting is online at [www.lindalliance.org/UI\\_Working\\_Partnership.asp](http://www.lindalliance.org/UI_Working_Partnership.asp). The top ten priorities have been developed into research recommendations, which members of the Partnership have been discussing with the Health Technology Assessment programme, to identify which ones may be suitable for funding.

#### Prostate Cancer

Prostate cancer is now the most common cancer in men in the UK - approximately 35,000 men are diagnosed each year. On 10 June, the Prostate Cancer Research Foundation, the Prostate Cancer Support Federation and the JLA held a meeting in London for those interested in finding out more about the Prostate Cancer Priority Setting Partnership. Attendees included men



Comedian Bob Monkhouse died of prostate cancer in 2003

who have or have had prostate cancer, their partners, medical professionals and researchers. There was strong support for the initiative, and subsequently a Partnership Protocol was agreed and signed up to by a steering group representing the patient and the clinician perspectives, which will lead the Partnership, with support from the JLA. The Prostate Cancer Research Foundation is funding two information specialists to assist with the identification of treatment uncertainties, and enter them in the UK Database of Uncertainties about the Effects of Treatments (UK DUETs).



The aim is to identify a top ten list of patients' and clinicians' research priorities by mid-2010. For further information please contact Lester Firkins at [lesterfirkins@mac.com](mailto:lesterfirkins@mac.com).



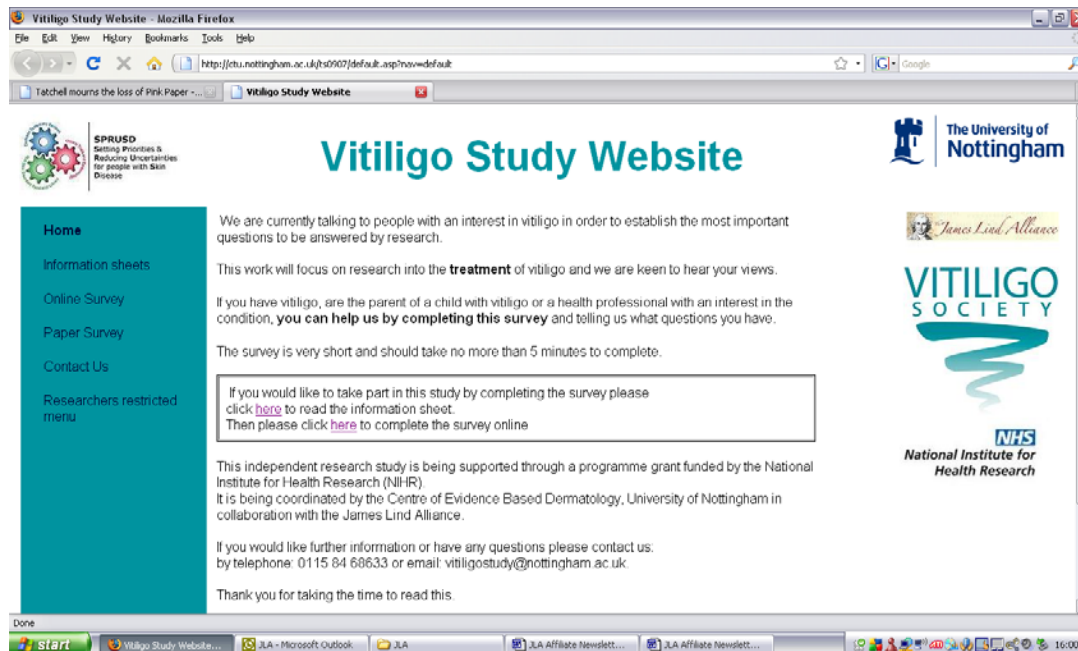
## Vitiligo

The Priority Setting Partnership for vitiligo, a condition in which patches of skin lack pigmentation, is part of a major project called Setting Priorities and Reducing Uncertainties for People with Skin Disease (SPRUSD) funded by the National Institute of Health Research.



**SPRUSD**  
Setting Priorities &  
Reducing Uncertainties  
for people with Skin  
Disease

A survey is now online, which is asking individuals with vitiligo, parents of children with vitiligo and healthcare professionals to submit any uncertainties about the treatment of vitiligo they would like to see addressed. So far, over 350 responses have been received, suggesting there are a significant number of potential uncertainties in vitiligo treatments, from both patient and clinician perspectives. The survey is available at [www.vitiligostudy.org.uk](http://www.vitiligostudy.org.uk) or by contacting the Centre of Evidence Based Dermatology on 0115 846 8633 / [vitiligostudy@nottingham.ac.uk](mailto:vitiligostudy@nottingham.ac.uk).



## Type 1 Diabetes

On 4 June the JLA held a workshop with patients, clinicians and organisations with an interest in type 1 diabetes. The aim of the workshop was to explore uncertainties about treatments for this condition and ascertain the level of support for setting up a Priority Setting Partnership. By the end of July a full account of this workshop will be available on the JLA website, including potential areas of treatment uncertainty in the various forms of insulin, insulin delivery mechanisms, blood glucose testing, psychosocial care, and others. We are hopeful that we will be able to progress this work in 2009/2010.



Participants learn about the JLA process

## Watch this space...

The JLA is being regularly approached by organisations interested in working with us to prioritise the uncertainties in the treatment of the conditions they represent. These conditions include: Tourette syndrome; stroke; schizophrenia; epilepsy; wound management; intensive care; ear, nose and throat disorders; learning disabilities; and birth trauma.

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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, please let us know by contacting the JLA office ([patkinson@lindalliance.org](mailto:patkinson@lindalliance.org)).

A full report of a new research commissioned by the JLA and carried out by TwoCan Associates is about to be published. This is available at [www.lindalliance.org/Scoping\\_research\\_priority\\_setting\\_PPI.asp](http://www.lindalliance.org/Scoping_research_priority_setting_PPI.asp).

A summary follows.



## **Scoping research priority setting, and the presence of patient and public involvement, with UK clinical research organisations and funders**

### **SUMMARY**

#### **Background**

Research on the effects of medical treatments often overlooks the shared interests of patients and clinicians. Questions important to both these groups may not be identified by others who influence the research agenda, such as industry or academia, and vital research areas may therefore be neglected.

The James Lind Alliance (JLA) was established in 2004 to bring patients and clinicians together to identify and prioritise the unanswered questions about treatments they agree are most important. The JLA aims to raise awareness among those who fund health research of what matters to both patients and clinicians so that clinical research is relevant and beneficial to the end user.

#### **Aims of the research**

The JLA commissioned this 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 translated into practical action.

The exercise involved a review of the websites of 104 UK clinical research organisations and further analysis of 55 of those, of which 52 fund research. Of these, 49 were voluntary sector organisations or medical charities and three were government funding bodies. Twenty two of those UK clinical research funding organisations that identify research priorities or commission research were interviewed, and a brief review of the literature on peer review and public and patient involvement in making funding decisions was conducted.

#### **Key findings**

##### *Identifying priorities for research*

- Most research funders operate in responsive mode, relying on researchers to submit ideas rather than themselves identifying priorities.
- Fewer than half the organisations surveyed state priorities for research. They are reluctant to place restrictions on researchers by asking them to address priority topics.
- The organisations which do identify research priorities do so for a range of reasons, in a number of different ways, including surveying patient members or researchers or simply relying on informal communication with them.

##### *Involving patients and the public*

- Few organisations identify the research priorities of clinicians and patients. Only a small proportion is aiming to address the priorities of both groups.



- There is a tendency to consult the research community as part of developing a research strategy, rather than consulting clinicians and patients.
- The type of patient and public involvement in decision-making processes varies between the organisations surveyed. Where patients and public are involved, they are more likely to be asked to review research proposals than to identify priorities for research which is important to them.
- There is a growing trend towards patient and public involvement among patient organisations that fund research, but the impact of this on funding decisions is not currently measured.

#### *Challenges to identifying research priorities*

- There is no agreed best practice or consistent approach for identifying priorities.
- Some organisations have faced resistance to developing a research strategy and to identifying research priorities, because researchers are concerned about the usefulness of the research and potential funding cuts.
- Where organisations have involved patients in the prioritisation process, they have found it difficult to interpret and summarise views accurately and to manage expectations of how quickly priorities can be addressed, if at all.

#### *The current influence of research priorities*

- Only a small number of organisations that identify priorities actually commission research to address them.
- A minority of organisations interviewed allocate funding solely to applications that address one of their identified research priorities.
- Most organisations do not take a systematic approach to addressing identified priorities and very few ring-fence budgets to fund prioritised research.
- Funding decisions are largely based on judgements about scientific merit, rather than on the relevance and importance of outcomes to end-users.

#### **Recommendations for the James Lind Alliance**

While this research adds to the evidence base around research priority setting and patient and public involvement, it also makes recommendations to help the JLA consider how to encourage UK clinical research funders to address the priorities of patients and clinicians, including:

- Encourage clinical research funders to rethink the purpose of identifying research priorities.
- Offer and promote a robust process for identifying and interpreting priorities.
- Share the results of its Priority Setting Partnerships, which bring patients, carers and clinicians together to identify and prioritise questions for research.
- Support Priority Setting Partnerships to develop more detailed commissioning briefs from lists of identified research priorities.
- Develop best practice for identifying and funding research priorities.

#### **For further information**

The full report is available at [www.lindalliance.org](http://www.lindalliance.org).



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## RECENT EVENTS

The JLA has participated in a number of events over the past three months, including the [www.healthtalkonline.org](http://www.healthtalkonline.org) launch and the Prostate Cancer Support Federation Conference mentioned above. Lester Firkins also spoke about the work of the JLA at the Edinburgh Royal Infirmary and at the Edinburgh Critical Care Group Study Day for Nurses and Allied Health professionals. Sally Crowe, Chair of the JLA Monitoring & Implementation Group, has joined several relevant research fora on behalf of the JLA, contributing to discussions on clinical research priority setting with both patient and clinician input.

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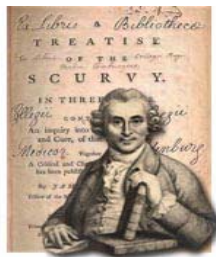
## FORTHCOMING EVENTS

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

### JLA, AMRC and National Voices joint event

The JLA, in partnership with the AMRC and National Voices, is hosting a 'think tank' on **Friday 9 October** to debate charity and industry relationships in clinical research. Speakers will include Sir Iain Chalmers from the JLA, Andrew Freeman, Head of Medical, Advocacy, Policy and Patient Programs, GSK Research and Development and Mauricio Silva de Lima, Medical Director, Eli Lilly, UK and Ireland.

This half-day event will be chaired by Simon Denegri, Chief Executive of the AMRC, will involve invited guests from across the relevant sectors. Attendance is by invitation only, but a report will be published after the event.



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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## IN PRINT

Brian Buckley and Adrian Grant. *What is the most effective management of neurogenic bladder dysfunction?* **BMJ** 2009;338:b659: describes the considerable uncertainty around managing this condition, to prevent urinary tract infection and preserve upper urinary tract health, continence and quality of life. The article refers to the JLA Urinary Incontinence Priority Setting Partnership.



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## ON THE WEB

Stay up-to-date with our work at [www.lindalliance.org](http://www.lindalliance.org). The site is regularly updated and now features an interactive noticeboard, to which you can add information on your organisation's events or other news relating to patient and clinician involvement in priority setting in research.

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## CURRENT AFFILIATES

The JLA currently has 179 Affiliates, most of whom 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. Organisations wanting to form or join a JLA Priority Setting Partnership must be Affiliates. An application form can be downloaded from [www.lindalliance.org](http://www.lindalliance.org).

One of our newest Affiliates is Tourettes Action, the UK's leading support and research charity for people with Tourette Syndrome and their families. The syndrome is an inherited neurological condition of which the key feature is tics - involuntary and uncontrollable sounds and movements. There are more than 300,000 people in the UK with Tourette Syndrome, including one schoolchild in every hundred, but as yet, its cause has not been established.

[www.tourettes-action.org.uk](http://www.tourettes-action.org.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 downloadable bibliography, along with an archive of JLA publications.

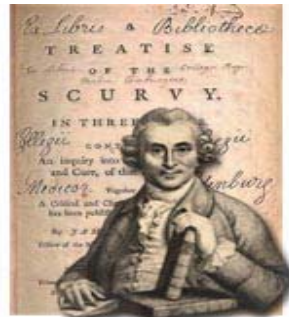
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## KEEP IN TOUCH

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 October.

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