



**Affiliates Newsletter – April 2010**

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**MESSAGE FROM THE CHAIR**

Dear Colleague,

Spring is finally in the air – and the freshness and growth is also wafting through the JLA (sorry, but the sun is shining and I couldn't resist the enthusiasm).

Our big event during the next quarter will be the launch of our Guidebook and we will ensure you are all sent the relevant link as soon as possible.

We are also entering the “conference” season and we have been invited to present the work of the JLA at many varied events – which is a delight because it gives us a real sense that people are definitely interested in what we are doing. As ever, we do not set out to say that ours is “the only way” of helping patients and clinicians work together – but it is a way that might be helpful.

A highlight of the last quarter was the conclusion of the Vitiligo Priority Setting Partnership (PSP). Meticulous preparation by all parties ensured that the final meeting was our best to date. That is to be expected as we continue to learn (we have only concluded three PSPs so far), but the evidence of process garnered along the way is invaluable.

Thank you for your continued interest and support – we do not take it for granted and we are pleased that the whole topic remains of interest to you.

Thanks, as always, for your support.

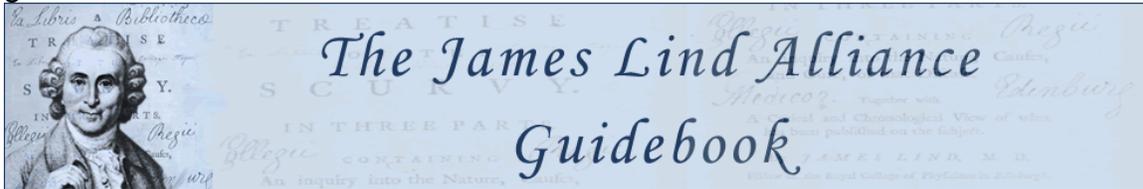
Lester Firkins, Chair, James Lind Alliance

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## NEWS

### The JLA Guidebook – to be launched 11<sup>th</sup> May

We are delighted to announce that the JLA Guidebook will be launched on 11<sup>th</sup> May. The Guidebook will be our online resource containing evidence-based guidance on the JLA process for identifying and prioritising treatment uncertainties. It will also contain the JLA Protocol, which partners will be expected to sign up to in order to commit to the JLA process. We hope that the Guidebook will encourage collaboration between patients and clinicians and will become a key source of their shared research priorities for researchers and commissioners to address. Affiliates will be alerted when the site goes live.



### MSc Clinical Research: Patient and Public Involvement in Research Module

University of  
Hertfordshire



The University of Hertfordshire is one of seven universities in England to offer the first wave of the part-time modular master's degree programme in Clinical Research. This programme is jointly funded and supported by the NIHR and Chief Nursing Officer (CNO). Recruitment for the master's programme is now complete, but the Patient and Public Involvement in Research module will be opened up to members of the wider community if there is sufficient interest. There are a limited number of additional places available to people who would like to gain knowledge and critical thinking in relation to public involvement in research. Individuals undertaking the module would join the nursing and allied health professional students on the course but would not be required to undertake any assessment. The module will be held over two two-day blocks: 25/26<sup>th</sup> May and 8/9<sup>th</sup> June 2010. JLA Chair, Lester Firkins, will be presenting the JLA perspective during the first block. For further information please contact Dr Diane Thompson: [d.1.thompson@herts.ac.uk](mailto:d.1.thompson@herts.ac.uk) or 07989 678943.

### UKCRC transition to partner-led model – progress report

The UK Clinical Research Collaboration's (UKCRC) transition to a partner-led model nears completion with the appointment a new Partnership Manager. Sarah Qureshi was appointed as the UKCRC's Partnership Manager towards the end of last year. This is just one in a number of changes associated with the transition.



At the UKCRC Board meeting in November 2009 the remaining mechanisms for delivering objectives were agreed, with lead Partners identified and, where



appropriate, supporting collaborative groups. All groups will review their work on an annual basis to assess whether there is a continued need for their activity. Sarah Qureshi can be contacted on [sarah.gureshi@ukcrc.org](mailto:sarah.gureshi@ukcrc.org). Further information is available in the UKCRC Winter Newsletter which can be downloaded from the UKCRC website: [www.ukcrc.org/publications/updates/](http://www.ukcrc.org/publications/updates/). Patient and Public Involvement activity has been allocated to INVOLVE.

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## JLA PRIORITY SETTING PARTNERSHIPS UPDATE

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

### Vitiligo

The Vitiligo Priority Setting Partnership is part of a wider initiative - Setting Priorities and Reducing Uncertainties for people with Skin Disease (SPRUSD). **Sally Crowe**, Chair of the JLA Monitoring & Implementation Group, reports:



“The final workshop of the priority setting process for treatment uncertainties for vitiligo on the 25<sup>th</sup> March was an exciting and busy event. People living with vitiligo and health professionals who provide treatment and care for them were equally represented on the day. Following scene-setting presentations from partners, we began with small discussion groups (four groups of 10), firstly sharing individual perspectives of the shortlisted research questions and moving on to shared priority areas, and agreeing a ranked order for the shortlist. Over lunch all the group rankings were aggregated. Newly mixed small groups discussed the new rank-ordered short list again. At tea time the second sets of ranked lists were aggregated and presented as a final short list for discussion by the whole group. A heated debate began with clinicians and then patients putting forward compelling arguments for placing of research questions in the final top ten. The order changed several times. Finally at 4.20 pm the whole group agreed the important final top 10 list.

“So, what was achieved? A consensus of 10 areas for research that really matter to the vitiligo community, as well as a fascinating day of well-ordered, humorous, compassionate and passionate debate by patients and clinicians. The SPRUSD team based in Nottingham will now work on developing a research protocol to

address one of the top ten priorities, and partners in the process will lobby for research in these important areas. Many people contributed to the process: the hundreds who first suggested areas of uncertainty in vitiligo treatments; a Steering Group that managed to condense these data to a 'long list' of over a hundred unique uncertainties; the team that built the voting website; the short list voters; and those who participated in the final workshop. Our heartfelt thanks goes to them all."

### Prostate cancer

The Prostate Cancer Priority Setting Partnership has now closed its survey of treatment uncertainties. In total, 22 forms were returned, which identified 134 potential uncertainties. After rephrasing and checking for repetition with peers, as well as removing those that were not valid or classified as treatment uncertainties, clinicians on the steering group have confirmed that there are 81 potential treatment uncertainties. Of these, 20 were submitted by healthcare professionals and 61 have originated from patients and patient support groups. An interim priority setting exercise is now in progress, and the final priority setting workshop, to agree on the top 10, will be held in September. Commentary on the Prostate Cancer PSP, and the challenges faced in engaging clinicians, is featured in the 14 April edition of the BMJ – see *In Print* below.

### Type 1 diabetes

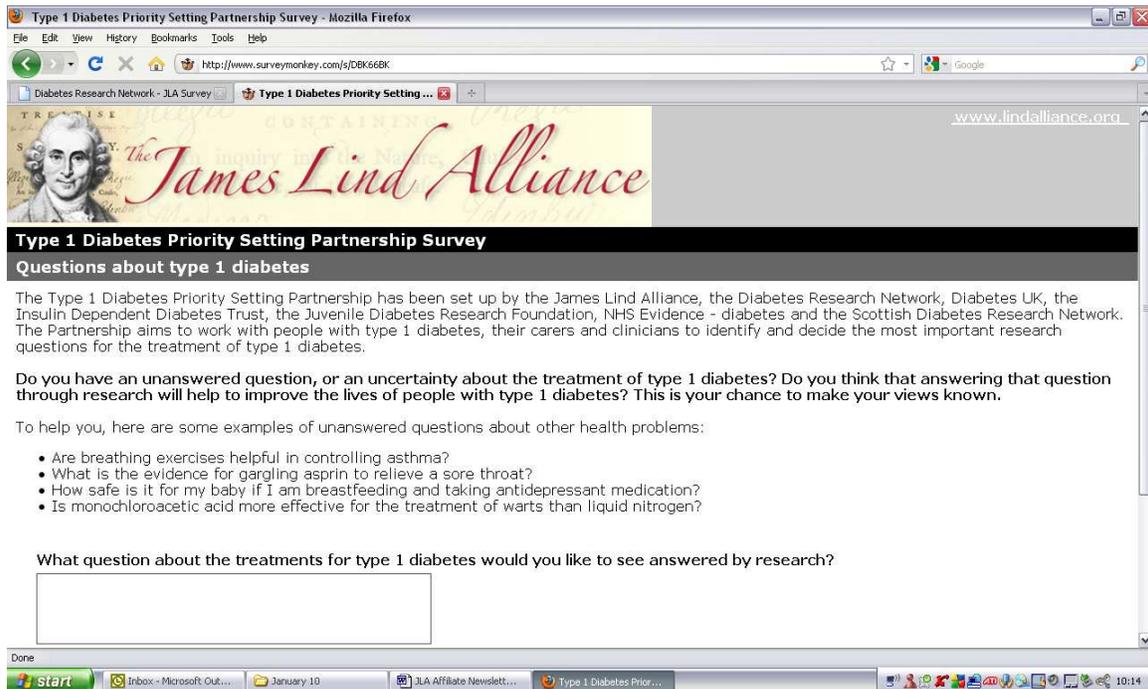


The Type 1 Diabetes Priority Setting Partnership is making excellent progress. The Partnership has been set up by the JLA, the Diabetes Research Network, Diabetes UK, the Insulin Dependent Diabetes Trust, the Juvenile Diabetes Research Foundation, NHS Evidence – diabetes, and the Scottish Diabetes Research Network. Type 1 diabetes occurs when the amount of glucose in the blood is too high. It is a leading cause of kidney failure, adult blindness, stroke, heart attacks and nerve damage and peripheral vascular disease leading to amputation. There are many unanswered questions about the treatment of Type 1 diabetes. The *NHS Evidence – diabetes 2009 Annual Evidence Update* identified 195 systematic reviews on all aspects of diabetes care, but only 13 of these were exclusively about treatments for Type 1 diabetes. Type 1 diabetes is increasing, particularly in the under 5s, and therefore it is important to get research evidence on the most effective ways of treating it.

Currently, the Partnership is gathering patients' and clinicians' unanswered questions about the treatment of Type 1 diabetes, through a survey which is open until 28<sup>th</sup> May. There are a number of ways to participate:



- online: [www.ukdrn.org/JLASurvey.html](http://www.ukdrn.org/JLASurvey.html)
- email / post: download the survey from [www.ukdrn.org/JLASurvey.html](http://www.ukdrn.org/JLASurvey.html) and send to
  - [Duets@nice.org.uk](mailto:Duets@nice.org.uk)
  - JLA, Summertown Pavilion, Middle Way, Oxford OX2 7LG
- telephone: call us on 01865 517622 to respond over the phone



The Type 1 Diabetes Priority Setting Partnership online survey

## Schizophrenia

The Schizophrenia Priority Setting Partnership is in the process of recruiting partner organisations representing patients, carers and clinicians to participate in the priority setting process. The UK DUETs schizophrenia module is in the process of being updated to include treatment uncertainties identified in recent literature and research recommendations, and the total number of uncertainties is expected to exceed 200. These will then be prioritised, and a top 10 agreed. For more information, contact Katherine Cowan: [katherine@katherinecowan.net](mailto:katherine@katherinecowan.net).

## Ear, nose and throat

This PSP has decided to concentrate on “Aspects of Balance Disorders”. A feature of this very distressing and limiting condition is the apparent lack of patient support groups. Therefore, as the PSP moves forward, we would welcome contact from any patient or patient group who would like to learn more about what we are doing. Please contact Lester Firkins at [lesterfirkins@mac.com](mailto:lesterfirkins@mac.com) who will put you in touch with the partnership’s administrator.



## Life after Stroke in Scotland

This PSP was started as a result of 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 develop a database specific to stroke rehabilitation in Scotland. The JLA priority setting process will be used to help them identify treatment uncertainties and to develop a prioritised list. An interesting element in this PSP is that, due to geography, it will not be feasible to have one single awareness-raising event to inform interested parties. Instead we will be developing a roadshow that can be taken around the country to local groups. This will be an interesting model which will help inform other PSPs in the future.

## Pressure ulcers

The team in York and Leeds who are leading this work have agreed a protocol for priority setting. Partners will be recruited over the summer of 2010. The Priority Setting Partnership will be part of a wider programme of work in wounds, details on which are at: [www.york.ac.uk/healthsciences/research/woundsprogramme.htm](http://www.york.ac.uk/healthsciences/research/woundsprogramme.htm).

If you are interested in finding out more about the partnership, please contact Sally Crowe ([sally@crowe-associates.co.uk](mailto:sally@crowe-associates.co.uk)) or Dr. Mary Madden ([mm538@york.ac.uk](mailto:mm538@york.ac.uk)).



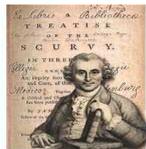
THE UNIVERSITY of York

Leeds Community Healthcare

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## RECENT EVENTS

### Building on Success – opportunities to progress patient and public involvement in research prioritisation and commissioning



INVOLVE

In February, the JLA, AMRC and INVOLVE hosted an event entitled *Building on Success – opportunities to progress patient and public involvement in research prioritisation and commissioning*, to draw on the lessons learned from the Patient and Public Involvement work of the UK Clinical Research Collaboration. The purpose of this event was to propose a number of actions, based on the evidence of the work that has been carried out by the three host groups, which



might improve the process and impact of Patient and Public Involvement in research prioritisation and commissioning. Attendance was by invitation only and included representatives from patient organisations, clinician groups and research commissioning bodies. A number of key themes were discussed, including:

- assessing and reporting evidence on public involvement in research prioritisation and commissioning
- creating incentives for researchers to research areas prioritised through processes in which patients/public have been included
- increasing the role and value of Patient and Public Involvement in established peer review processes for commissioning research

A report is currently being drafted and an update will follow in the next newsletter.

Commenting on the event, Simon Denegri, Chief Executive of the AMRC said:

*“I was pleased that the event provoked a robust and candid discussion among all participants. It did not result in many solid action points from the meeting. But the overriding message for me was that the community must work harder to follow up the recent NIHR/INVOLVE report on impact in demonstrating and communicating the value of public and patient involvement to researchers and funders. We have come a great distance in the last ten years but we have much work to do.”*



Simon Denegri

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## **FORTHCOMING EVENTS**

### **International and interdisciplinary intensive care summer school**

*A patient's journey through intensive care and recovery: learning from different disciplinary approaches*

Lester Firkins will be speaking at Edinburgh University's intensive care summer school, which takes place from 6<sup>th</sup> to 9<sup>th</sup> September. He will be addressing the methodological challenges of involving patients and families in intensive care research. For details, or to book a place, go to [www.crfr.ac.uk/events/summerschool.html](http://www.crfr.ac.uk/events/summerschool.html).



Lester will also speak about the work of the JLA on 27th April at the Scottish School of Primary Care Conference, Perthshire, and on 28th April at the Tayside Clinical Trials Unit Seminar in Dundee. He will be speaking at the Head and Neck Cancer workshop on 20<sup>th</sup> May, in Bristol

**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

Halls E. *Personal View: Where are all the clinicians when you need them?* BMJ 2010;340:c1845

Emma Halls, Chief Executive of the Prostate Cancer Research Foundation, and key player in the JLA Prostate Cancer Priority Setting Partnership, makes an impassioned plea to clinicians:

*Having spent the past 12 months working with patient groups and clinicians on a project to identify treatment uncertainties in prostate cancer, I have been amazed at the way people and organisations working in the same field don't speak to each other. Have we become so competitive that we can't see that working together is good, if not essential? My frustration is growing, and the BMJ seems a good place to ask doctors: "Why the lack of communication?" Where is your culture of collaboration in my field of prostate cancer? Do you feel you have your own show, and all the answers?*



Oliver S. *Pioneer Profile: Lester Firkins. The Patient: Patient-Centered Outcomes Research.* 1 March 2009 - Volume 2 - Issue 1 - pp 1-4  
Profile of JLA Chair Lester Firkins' journey into patient and public involvement in clinical research.



Serrano-Aguilar P et al. *Patient involvement in health research: A contribution to a systematic review on the effectiveness of treatments for degenerative ataxias*. Social Science & Medicine. September 2009, vol./is. 69/6(920-925), 0277-9536

This article describes a study to incorporate patients' perspectives in the design of a systematic review of the effects of treatments for degenerative ataxias .



The article mentions the work of the JLA as a recent initiative of collaboration between patients and clinicians to identify priorities for research on the effects of treatments, and to carry out systematic reviews when these are needed.

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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 has 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 190 Affiliates, most of whom are listed on our website, with links to their websites. Affiliation is a free and simple 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 [http://www.lindalliance.org/Affiliate\\_application\\_online.asp](http://www.lindalliance.org/Affiliate_application_online.asp)



Our latest Affiliate is Ian Needleman, Professor of Restorative Dentistry and Evidence-Based Healthcare at UCL Eastman Dental Institute. Ian is also an Editor with the Cochrane Oral Health Group, Director of the International Centre for Evidence-Based Oral Healthcare and recently appointed Public and Patient Involvement lead for oral health, UCLH/UCL Comprehensive Biomedical Research Centre. “My clinical and research interests are in achieving the best oral healthcare with an increasingly strong focus on public and patient involvement”, he explains. “We are currently developing a research study to investigate prioritisation of oral health research and these areas of interest are very close to the core objectives of the JLA.”



Ian Needleman

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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, public and clinician involvement (PPCI) 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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## **CORRECTION**

In the January newsletter we stated that the UK Clinical Research Collaboration (UKCRC) had been disbanded. The UKCRC itself has not been disbanded, but its Patient and Public Involvement programme has been concluded and activity in this area has now been taken on by INVOLVE. Apologies for any confusion caused.

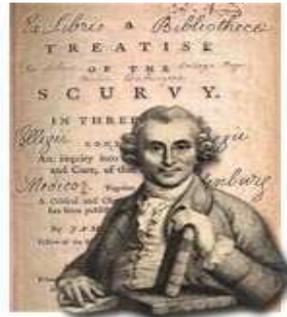
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## KEEP IN TOUCH

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 2010.

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