



## Affiliates Newsletter – September 2010

---

### MESSAGE FROM THE CHAIR

Dear colleague,

I am delighted to bring you the JLA Affiliates Newsletter, which we are now publishing on a bi-monthly basis. This edition is packed with news of our Priority Setting Partnerships, and also features a fantastic practical guide to involving patients and the public in research, for which thanks go to our colleague Dr. Thomas Kabir, from the NIHR Mental Health Research Network's Service Users in Research Project.

As you'll read in the In Print section of the Newsletter, the JLA is really delighted to have been the subject of a second *Lancet* article. In November 2004, the *Lancet* covered the JLA's launch<sup>1</sup>. At that time we were peering into the unknown as regards how and if we would successfully start to address our aims and objectives. In August 2010 the *Lancet* published a further comment which summarises the progress to date and indeed acknowledges the excitement both past and to come!

This publication means a great deal to us as it provides a timely benchmark and stepping stone for the years to come. We are acutely aware that we are continuing to learn, but to be embraced within the establishment of literature is a great encouragement. My sincere thanks go to Sophie Petit-Zeman, John Scadding and editors at the *Lancet* for taking a huge amount of time to perfect this article.

Finally, you will read that we have re-launched our Affiliates Programme. So please, do continue to spread the word about the JLA, and if you've not signed up as an Affiliate, what are you waiting for?!

Thanks, as always, for your support

Lester Firkins, Chair, James Lind Alliance

---

<sup>1</sup> Partridge N, Scadding J. The James Lind Alliance: patients and clinicians should jointly identify their priorities for clinical trials. *Lancet* 2004; **364**: 1923–24.

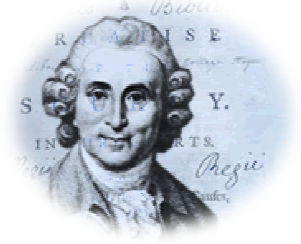


---

## NEWS

### **JLA Affiliates Programme needs YOU!**

Following feedback from our members, the JLA has redesigned the process of Affiliation to make it much quicker and easier to sign up. We are asking you, our existing Affiliates, to help us reach a wider audience by encouraging your colleagues and networks to Affiliate too. In the next few weeks you will receive an email from us designed to be forwarded on. Alternatively, simply send this newsletter on to them. To anyone reading this who is NOT already an Affiliate, please visit our website to find out more and to apply online: [www.lindalliance.org/Affiliates-Programme.asp](http://www.lindalliance.org/Affiliates-Programme.asp). Or call our office on 01865 517635 to be sent an application form. It'll take you less than two minutes, but will link you to an ever-expanding network of decision-makers, influencers and pioneers committed to involving patients and clinicians in research priority setting.



### **NICE research recommendations process and methods guide**

A guide has been developed by the National Institute for Health and Clinical Excellence (NICE) to support guidance-producing centres in the process of making research recommendations through a step-by-step approach. The process includes: identifying uncertainties; formulating research recommendations and research questions; and prioritising and communicating them to researchers and research funders. To support the NICE guidance production teams/groups with the implementation of this updated process, NICE Research and Development is holding two workshops. Speakers will include the JLA's Lester Firkins, who will talk about priority setting methods, and Mark Fenton (Editor, UK DUETs), who will discuss treatment uncertainties.



"The collection of uncertainties about the effects of treatment, and then asking patients and clinicians to prioritise their shared uncertainties for funding by UK research funders, seems to be ideas whose time has come," says Mark Fenton. "NICE is developing its methods to include this type of approach to run in parallel with its guideline development work. This is an important step in mainstreaming the JLA approach to prioritising treatment uncertainties."

The guide is available on the NICE website at [www.nice.org.uk/media/46F/72/ResearchRecommendationManual.pdf](http://www.nice.org.uk/media/46F/72/ResearchRecommendationManual.pdf).

### **NIHR Systematic Reviews brochure**

The National Institute for Health Research is a global leader in producing and promoting systematic reviews – high-quality syntheses of research evidence to support decision-making in health and social care - and NIHR has recently produced a leaflet about them. Lester Firkins, JLA Chair, represents the JLA on the UK Reviews Infrastructure Advisory Board.

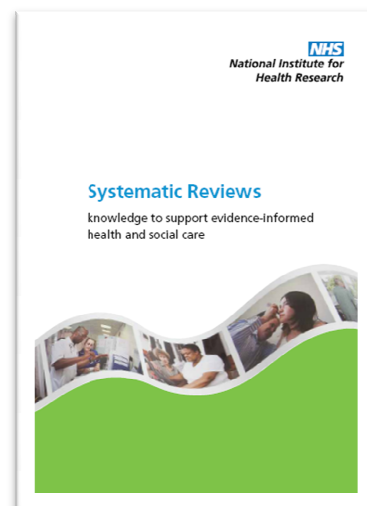
*Systematic Reviews: knowledge to support evidence-informed health and social care* explains the workings of the NIHR Systematic Review Infrastructure (NSRI), which comprises the UK Cochrane



Centre and Cochrane Review Groups, the Centre for Reviews and Dissemination, and the Health Technology Assessment (HTA) Reviews (TARs).

In particular, the leaflet notes: “Cochrane Review Groups take account of the views of patients and clinicians when prioritising topics for review. For example, the Cochrane Review Group covering incontinence recently shortlisted two reviews following publication of a list of topics prioritised by patients and clinicians through a James Lind Alliance Priority Setting Partnership.”

The leaflet can be downloaded from [www.nihr.ac.uk/research/Pages/Systematic\\_Reviews.aspx](http://www.nihr.ac.uk/research/Pages/Systematic_Reviews.aspx).



.....

## JLA PRIORITY SETTING PARTNERSHIPS UPDATE

JLA Priority Setting Partnerships (PSPs) 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 visit [www.JLAguidebook.org](http://www.JLAguidebook.org) or contact Patricia Atkinson ([patkinson@lindalliance.org](mailto:patkinson@lindalliance.org)).

### Prostate cancer

The Prostate Cancer PSP will be holding a final workshop to set priorities for prostate cancer research on Monday 4 October in London. The participants (patients and clinicians) will consider, discuss and rank 32 unanswered questions about prostate cancer. The questions, which have been shortlisted from a longer list of uncertainties identified by patients, clinicians and existing research, are diverse. For example, “Is there a vaccine that can prevent prostate cancer?”, “Do variations in GP awareness of prostate cancer affect outcomes?”, “Can needle biopsy of the prostate cause cancer to spread?” and “How do we prevent radical prostatectomy causing urinary incontinence?”. Sandy Tyndale-Biscoe, Chairman of the Prostate Cancer Support Federation, one of the two charities that initiated the work (the other is the Prostate Cancer Research Foundation), comments: “The emerging results of this exercise are very interesting, and encouraging. It seems that what patients and clinicians want from research is not always where the money is being spent. We urge funders to look very hard at the results, and take them into account when deciding about future research directions.”



Tyndale-Biscoe

### Type 1 diabetes



The PSP in Type 1 diabetes is about half way through its work. The initial survey of treatment uncertainties yielded a large response from patients, carers and clinicians alike. An independent information scientist, Ann Daly, has been working through the responses throughout the summer. With the help of the partners



she has defined the survey responses as treatment- and non-treatment-related, and has allocated them to categories. Staff at NHS Evidence – Diabetes have also been very helpful in this task, providing evidence for some of the more obscure uncertainties, and commenting on categories etc. “So far we have a total of 1,142 unique treatment related research questions,” explains Sally Crowe, Chair of the JLA Monitoring & Implementation Group, and Chair of this PSP, “So we have quite a task ahead to agree the most important ten of these! The Steering Group will meet in October to review these questions and plan the first stages of priority setting. The aim of this next phase of activity will be to reduce the ‘long list’ of 1,142 uncertainties submitted to a more manageable ‘short list’ for final priority setting. Ann will be writing up her experiences for the record, and for those interested in information methodology. As ever, what we learn will be filtered into the JLA Guidebook so that everyone can benefit from our collective experience.”

If you or your organisation are interested in being involved in the next stages of this PSP please contact Sally Crowe on [sally@crowe-associates.co.uk](mailto:sally@crowe-associates.co.uk) or ring 01844 216929.

## Schizophrenia

The Schizophrenia Priority Setting Partnership is due to start its interim prioritisation exercise, in which partner organisations and individuals representing patients and clinicians will shortlist their top 10 uncertainties about the effects of

treatments from the UK DUETs schizophrenia module. The module contains over 200 unanswered questions about schizophrenia treatment which have been gathered from patients, clinicians and research recommendations. Jo White has recently been recruited to work as a Research Assistant, coordinating the priority setting process. She is based at Swansea University's School of Medicine. “I am absolutely thrilled to be joining and working on the team,” says Jo, “And I thoroughly looking forward to being involved.” Jo worked previously for Professor Peter Huxley and Dr Sherrill Evans in the Centre of Social Work and Social Care Research based at Swansea University on a national team funded project (NIHR Service Delivery and Organisation Programme) looking at the integration of social care staff within community mental health teams across England and Wales. For further details of the PSP please contact Katherine Cowan ([katherine@katherinecowan.net](mailto:katherine@katherinecowan.net)) or Jo White ([j.white@swansea.ac.uk](mailto:j.white@swansea.ac.uk)).



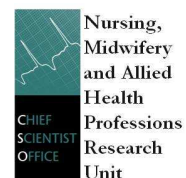
Jo White



## Life after stroke in Scotland

A steering group for a PSP focussing on ‘Life after Stroke in Scotland’ was established in January 2010. This priority setting project is being carried out as part of a larger project ([www.askDORIS.org](http://www.askDORIS.org)), which is funded by the Scottish Government Health Directorate and hosted by the Chief Scientist Office Nursing Midwifery & Allied Health Professions Research Unit. In contrast to other PSPs, the steering group has decided NOT to hold one key ‘launch’ event to identify partner organisations and start the process of gathering uncertainties. Instead, this steering group is going to take a ‘roadshow’ around Scotland, aiming to attend existing stroke related groups

and functions to give a short, standardised presentation about the Life after Stroke PSP. The steering group aims to visit and present the project to at least one patient group in every mainland NHS Health Board area in Scotland. In addition to targeting patient/carer groups, the PSP will also take the ‘roadshow’ to





relevant national stroke-related meetings and conferences. Plans are underway to attend the Scottish Stroke Nurses Forum, the Scottish Stroke Research Network and the UK Stroke Forum annual conferences. Other patient and health professional groups will be sent information and requests to participate by either post or email. To ensure inclusiveness of stroke patients who have specific impairments, information will also be available in audio formats and accessible to people with aphasia, a disorder that results from damage to parts of the brain that are responsible for language. The steering group hopes to have completed the collection of uncertainties by the end of December 2010. For more information, please contact Dr Alex Pollock ([Alex.Pollock@gcu.ac.uk](mailto:Alex.Pollock@gcu.ac.uk)).

### Ear, nose and throat – aspects of balance

This PSP has been established to identify and prioritise uncertainties about the treatment of balance disorders. There is great uncertainty around the causes of and treatment for balance disorders. In a recent interview in *The Sunday Telegraph*<sup>2</sup>, Jessica Ennis, Britain's world heptathlon champion and London 2010 Olympics hopeful, revealed that she had recently suffered from an inner-ear virus that left her so dizzy and nauseous that she was unable to train for a fortnight.

*“It did make me think about the Olympics because I’ve suffered from the same thing before,” she says. “The worry is that it could come on at any time but the doctors don’t know what actually causes it. I had it once when I was about 13 or 14 but it only lasted about a day so it didn’t affect me that much. But then I had it again about four years ago and it lasted two or three days. This time it was obviously a lot worse, so it did make me panic. It made me think that everything I’ve done could suddenly go out of the window.”*



Jessica Ennis

To read the full interview, go to

[www.telegraph.co.uk/sport/othersports/olympics/7908980/London-2012-Olympics-Jessica-Ennis-is-an-athlete-with-a-mission.html](http://www.telegraph.co.uk/sport/othersports/olympics/7908980/London-2012-Olympics-Jessica-Ennis-is-an-athlete-with-a-mission.html).

The Aspects of Balance PSP has launched an online survey to collect patients', carers' and clinicians' unanswered questions about the treatment of balance disorders. To take part, please go to [www.surveymonkey.com/s/TQ5DTZK](http://www.surveymonkey.com/s/TQ5DTZK). You can access a PDF version of the survey on the JLA website ([www.lindalliance.org/pdfs/ENT/Harvesting\\_Form\\_Final.pdf](http://www.lindalliance.org/pdfs/ENT/Harvesting_Form_Final.pdf)) and post it to Jo White, ENT UK, The Royal College of Surgeons of England, London WC2A 3PE. Closing date for submission of uncertainties is Friday 1st October 2010. If you would like any further information, contact Jo White [jo@entuk.org](mailto:jo@entuk.org).

### Pressure ulcers



Pressure ulcers (pressure sores, bed sores, decubitus ulcers) are painful for patients and distressing for patients and carers. Pressure ulcer research is currently the sphere of a small group of experts funded by industry or the NHS. Public involvement in and awareness of wounds research is minimal.

<sup>2</sup> Hart, S. (2010) London 2012 Olympics: Jessica Ennis is an athlete with a mission. *The Sunday Telegraph*. 25 July.



The JLA Pressure Ulcer PSP has been established to address this and is holding a workshop on 30<sup>th</sup> November. It is inviting patients, carers, clinicians and partner organisations to register their interest in attending at [www.jlapressureulcerpartnership.co.uk](http://www.jlapressureulcerpartnership.co.uk). Patients, carers and clinicians are also being asked to submit their unanswered questions about the treatment of pressure ulcers via the website. For further information, 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)).

### **Intensive Care Units (ICU)**

As reported in July, the JLA has been invited by the Scottish Intensive Care Society, the Edinburgh Critical Care Research Group and the University of Edinburgh to work on a programme to identify priorities for further research around the quality of life of ICU survivors – based on the outcomes prioritised by patients and clinicians. Currently there appears to be little evidence about how patients should be managed during the transition from intensive care units to general wards, and from wards to home. The first stage will be a seminar in Edinburgh on 22 October. For further information please contact Professor Timothy Walsh ([timothy.walsh@ed.ac.uk](mailto:timothy.walsh@ed.ac.uk)) or Pam Ramsay ([pam.ramsay@luht.scot.nhs.uk](mailto:pam.ramsay@luht.scot.nhs.uk)).



---

### **Being Useful ... Involving People in Research**

By Thomas Kabir, NIHR MHRN Service Users in Research Coordinator

My name is Thomas Kabir. I am the Coordinator of the national service user involvement arm of the NIHR Mental Health Research Network (MHRN). I am also involved with the JLA's Schizophrenia Priority Setting Partnership.

I have been asked to say a little about how I would recommend actively involving people in research. The following is just my opinion, but I hope that it is useful...

*1. When you ask for people's opinions on something, make changes!*

One gripe many people have about consultations etc carried out by public sector bodies is that nothing ever changes. This breeds a poisonous kind of cynicism. So when you do ask for someone's opinions about a proposal (or anything else) it does wonders to actually make a show of how their contributions have really made a difference.

*2. Don't try to please everyone*

There are so many different opinions out there about how to involve people and what their role in research is. Frankly, you are doing well if you satisfy half the people that you have to deal with.

*3. Allow people to identify themselves in a way that they feel comfortable with*

Patient, service user, consumer? There are so many different ways that a person who wants to get involved in research might want to be referred to. It makes sense to allow him/her to choose (within reason) a term that they would be comfortable being identified with.



Thomas Kabir



#### 4. *Make every effort you can to be useful to researchers*

This is at the heart of what I want to say. The more useful people are to researchers the more involvement opportunities will come your way. Another result of this is that researchers will be more likely to come to believe that involvement really can improve the quality of their research. A good example of involvement which can really help researchers is to ask patients to review patient information sheets and consent forms before the researcher applies to an ethics committee for ethical approval. One of the most common reasons for studies to be rejected by an ethics committee is because the information sheet is gobbledegook. Patient involvement can really make a difference here.

#### 5. *Pay people's expenses*

Certainly in mental health a lot of people who get involved are on benefits. For these people even very modest costs can mean that getting involved is simply not possible. So I would strongly recommend that (at the very least) the expenses of people who get involved be paid.

#### 6. *Give people a plain English introduction to the project that they are getting involved with*

Research is laden with jargon. In my experience it pays handsome dividends to provide involved people with a clear plain English introduction to whatever research project they are getting involved with. Without one, people are left struggling to understand what the research is about let alone make a contribution as to how it might be done better.



To find out more about the MHRN and how we involve people please visit [www.mhrn.info](http://www.mhrn.info).

Thomas Kabir: [thomas.kabir@kcl.ac.uk](mailto:thomas.kabir@kcl.ac.uk)

---

## RESEARCH

### **Asthma PSP: what happened next?**

A paper has been published on the JLA website documenting research activity following the Asthma treatment uncertainty priority setting exercise. The paper captures relevant recent research activity following the completion of the PSP in 2007. The activity recorded ranges from uncertainties being submitted to commissioning research programmes, to partner organisations' own research and strategy development.

“Collecting, recording and interpreting the next steps and impact of research priorities derived from a priority setting process is an important part of the jigsaw puzzle for the James Lind Alliance and its partner organisations,” says Sally Crowe, chair of the JLA’s Monitoring & Implementation Group. “We have to ask ourselves: *Was it all worth it? Did anything change as a result? Are the priorities different to current research strategies and plans?* This report is a start in capturing progress with priorities, and our ongoing contact and dialogue with partners will help ensure that we keep abreast of developments.”

The report can be accessed from the JLA website at:

[www.lindalliance.org/pdfs/Asthma/Post\\_JLA\\_priorities\\_Asthma\\_January\\_2010.pdf](http://www.lindalliance.org/pdfs/Asthma/Post_JLA_priorities_Asthma_January_2010.pdf).



---

## RECENT EVENTS

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

The report of this event has been published. It describes a ‘think tank’ event jointly organised by the Association of Medical Research Charities (AMRC), the James Lind Alliance (JLA) and INVOLVE, with the support of the UK Clinical Research Collaboration. The event brought together representatives from large and small research funding organisations, research commissioners and other groups and individuals with experience of patient and public involvement in research priority setting and commissioning. The purpose of the meeting was to reflect on progress and to consider the future development of patient and public involvement in research priority setting and commissioning processes.



[www.lindalliance.org/pdfs/JLA Internal Reports/Building on Success Final 23 Sept 10.pdf](http://www.lindalliance.org/pdfs/JLA%20Internal%20Reports/Building_on_Success_Final_23_Sept_10.pdf)

---

## FORTHCOMING EVENTS

Sir Iain Chalmers, a co-founder of the JLA, and Lester Firkins, the JLA’s Chair, will both be speaking at the 4th NIHR Trainee Conference on 30 November in Manchester.

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

---

## IN PRINT

Petit-Zeman, S. *et al.* (2010) ‘The James Lind Alliance: tackling research mismatches’, *The Lancet*, Vol. 376, pp. 667-669. Summarises the progress and achievements of the JLA since its launch in 2004.

Thomas, R. *et al.* (2010) ‘Identifying and prioritising epilepsy treatment uncertainties’, *Journal of Neurology, Neurosurgery and Psychiatry*, Vol. 81, pp. 918-921.

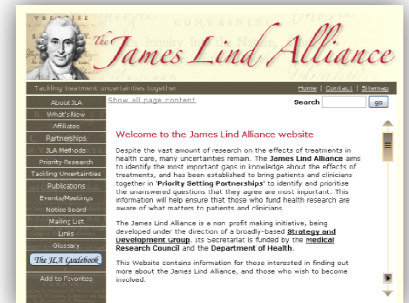
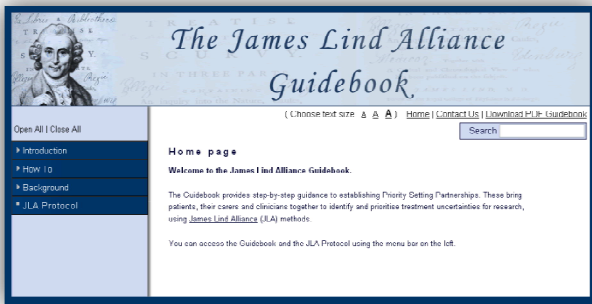




Written on behalf of members of the Wales Epilepsy Research Network (WERN) and the JLA, this paper describes an exercise carried out by WERN, the Cardiff University School of Medicine and others to identify and prioritise uncertainties about epilepsy treatment identified from people with epilepsy, their carers, and epilepsy clinicians. This has resulted in the creation of a comprehensive epilepsy module in UK DUETs.

## 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.

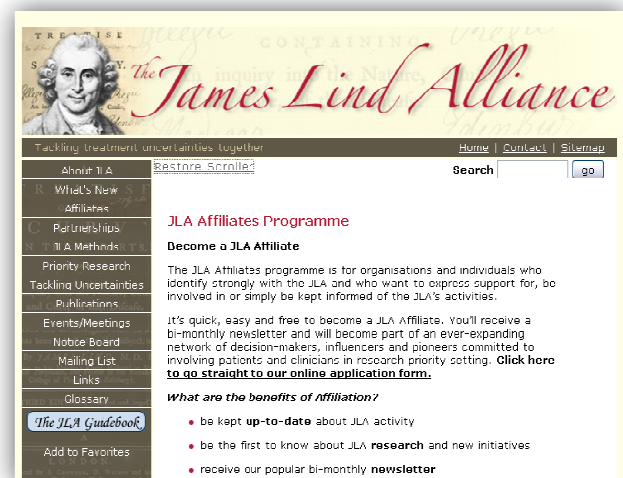


For practical guidance on establishing a PSP and working with patients and clinicians to identify and prioritise treatment uncertainties for research, please visit our online Guidebook: [www.JLAGuidebook.org](http://www.JLAGuidebook.org). The Guidebook features examples of existing PSPs, including documents and templates to download and use.

## CURRENT AFFILIATES

The JLA Affiliates programme is for organisations and individuals who identify strongly with the objectives of the JLA, and who want to express support for, be involved in or simply be kept informed of the JLA's activities.

It's quick, easy and free to become a JLA Affiliate. You'll receive a bi-monthly newsletter and will become part of an ever-expanding network of decision-makers, influencers and pioneers committed to involving patients and clinicians in research priority setting. If you're not already an Affiliate, please go to [www.lindalliance.org/Affiliates-Programme.asp](http://www.lindalliance.org/Affiliates-Programme.asp) to sign up.



The JLA currently has 210 Affiliates, which are listed on our website. Our most recent Affiliate is the Centre of Academic Primary Care at the University of Aberdeen. "Our research programme - Engaging with Older People and their carers to develop Interventions for the self-management of Chronic pain (EOPIC) - has a strong focus on working with service users as equal partners," says Dr Pat Schofield, Director of the Centre. "We therefore agree with the objectives and principles of the James Lind Alliance." For further information please visit [www.abdn.ac.uk/nursing](http://www.abdn.ac.uk/nursing).



Dr. Pat Schofield



---

## WANT TO FIND OUT MORE?

If you are new to the JLA or simply want to find out more about patient and clinician involvement in research priority setting, please visit [www.lindalliance.org](http://www.lindalliance.org). In the Publications section you will find a downloadable bibliography, along with an archive of useful JLA publications.

---

## 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 November 2010.

Katherine Cowan  
James Lind Alliance  
Summertown Pavilion  
Middle Way  
Oxford OX2 7LG

[katherine@katherinecowan.net](mailto:katherine@katherinecowan.net)

[www.lindalliance.org](http://www.lindalliance.org)

