



Affiliates Newsletter – July 2010

MESSAGE FROM THE CHAIR

Dear Colleague,

I am pleased to send you our latest Newsletter.

I cannot profess to having studied the entire document in detail, but I would like to quote a section from the latest Government health white paper:

We want the principle of "shared decision-making" to become the norm: no decision about me without me. International evidence shows that involving patients in their care and treatment improves their health outcomes... It can also bring significant reductions in cost... This is equally true of the partnership between patients and clinicians in research, where those institutions with strong participation in clinical trials tend to have better outcomes.

The JLA and all its supporters should draw great encouragement from this.

Many of the Priority Setting Partnerships are making excellent progress, so in order to keep you better informed, we have decided to increase production of this newsletter to bi-monthly rather than quarterly. If you are an Affiliate of the James Lind Alliance and have something you would like to contribute, please feel free to contact the Editor, Katherine Cowan: katherine@katherinecowan.net.

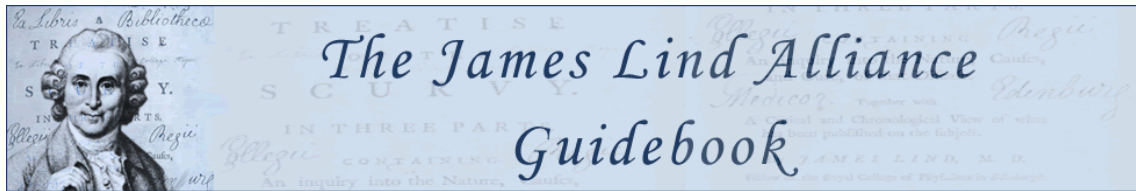
We are all delighted by the positive response to the launch of our Guidebook. We hope that this will continue to stimulate interest and indeed make it easier for more groups to become involved.

Thanks, as always, for your support.

Lester Firkins, Chair, James Lind Alliance

NEWS

Introducing the JLA Guidebook



The JLA Guidebook was launched on 11th May and in its first month alone was accessed over 2000 times. The Guidebook, which is online at www.JLAguidebook.org, is the JLA's practical guide to establishing a Priority Setting Partnership in which patients and clinicians work together to prioritise treatment uncertainties for research. The launch saw coverage in a wide range of publications, including *Nature Medicine*, the *Times Eureka Blog* and *Cochrane Collaboration News*. It was also the subject of a Cochrane Collaboration podcast for International Clinical Trials day. See page 6 for more information.

JLA Report for 2008-2010

The JLA has published its report of work done between April 2008 and March 2010. It has been an exciting period in the JLA's history, with a marked increase in priority setting activity and our continued contribution to the debate on patient and clinician involvement in research priority setting. Key achievements over the two years include:

- Two partnerships completed the priority setting process; urinary incontinence and vitiligo, while nine further partnerships were established and are underway.
- A number of studies exploring the nature of research priority setting and the involvement of patients and clinicians were commissioned, including *A Systematic Map of Studies of Patients' and Clinicians' Research Priorities* (Stewart R and Oliver S, JLA 2008) and *Scoping Research Priority Setting, and the Presence of Patient and Public Involvement, with UK Clinical Research Organisations and Funders* (Staley K and Hanley B, JLA 2008).
- Funding has been secured for the JLA until March 2013.

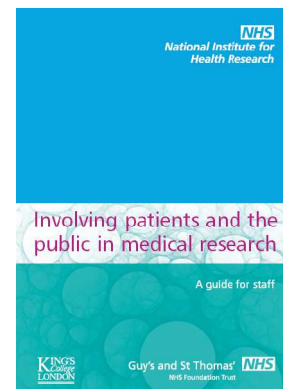
The full report, and annexes, can be downloaded from the JLA website:

www.lindalliance.org/JLA_Report_2008-2010.asp.

We have also published our **objectives** and **key drivers** for 2010-2013 on the JLA website. To find out more, go to www.lindalliance.org/Objectives.asp.

Involving patients and the public in medical research

Guy's and St Thomas' NHS Foundation Trust has recently produced a step-by-step guide to involving users in the research process. *Involving Patients and the Public in Medical Research* is aimed at staff and explains what user involvement entails, why it is important and how users can be involved in the research process. It also makes reference to the JLA as a source of support. For further information, contact Sophie Auckland, comprehensive Biomedical Research Centre User



Involvement Manager, on 020 7188 6333, or email her at sophie.auckland@gstt.nhs.uk. Alternatively, go to www.guysandstthomas.nhs.uk/healthprof/researchanddevelopment/biomedicalresearch/user_involvement_staff.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 or contact Patricia Atkinson (patkinson@lindalliance.org).

Prostate cancer



The Prostate Cancer PSP is making progress, as Emma Halls (left), Chief Executive of the Prostate Cancer Research Foundation, reports: "We are still evaluating the initial results with a view to getting a final top 30 in the coming weeks." As all those who have participated in PSPs will know, the priority setting stages can be challenging and it is important to get them as right as possible. "We have been slower than anticipated but we want to ensure that we don't rush the process and let down all the men with prostate cancer and their families," explains Emma. "We hope now to hold the final meeting in early October." For more information on the Prostate Cancer Priority Setting Partnership, contact Lester Firkins on lesterfirkins@mac.com.

Type 1 diabetes



The Type 1 Diabetes PSP has now closed its online survey. In total, almost 600 individuals submitted nearly 1050 treatment uncertainties. "We were really pleased with the response to the survey," said the JLA's Sally Crowe. "We took steps to capture the profile of the respondents, which meant we could identify where particular groups were under-represented, and then target them. Initially we had a disproportionately low response from healthcare professionals working in a paediatric setting and parents of children with type 1 diabetes. The steering group concentrated its efforts on those groups and within a couple of weeks, the numbers had doubled." The collected uncertainties are currently 'raw' and are now being checked by an information specialist and the members of the steering group. This process involves carefully sifting through the submissions and formatting them into a standard language, as well as combining duplicates. They then need to be verified as true uncertainties, to ensure they have not already been answered by existing research. The final list is therefore expected to be much less than 1050, and will be added to the UK Database of Uncertainties about the



Effects of Treatments (UK DUETs). This will be the list with which the PSP will work to prioritise its top 10. For more information, contact Sally Crowe: sally@crowe-associates.co.uk.

Schizophrenia

The Schizophrenia PSP is in the process of finalising its 'long list' of treatment uncertainties from UK DUETs. There are 228 uncertainties in the list, although this is likely to be reduced slightly as there are still some duplicates to track down and remove. Mark Fenton, Editor of UK DUETs, is leading this complex element of the partnership's process, and explains what the work has involved:



“Updating the UK DUETs Schizophrenia module has given me the opportunity to add new treatment uncertainties from a number of different sources, including new research recommendations in the Cochrane Schizophrenia Group’s systematic reviews and an updated NICE Clinical Guideline. I’ve also been involved in a pilot project to see if it is possible to identify treatment uncertainties which emerged from in-depth qualitative research into patient experiences, led by experts from Healthtalkonline (www.healthtalkonline.org). It’s not a quick process. Simply undertaking the searches to check that all submissions *are* treatment uncertainties can take weeks. When you get more narrative text, which also describes someone’s lifetime history of their illness, it can be very difficult to identify a treatment uncertainty; it requires input from both patient and clinician representatives. We are nearly at the point at which the completed list can be circulated to the wider membership of the PSP, so we should hopefully be moving towards a first round of ranking, leading to a final priority setting meeting later in the year.”

For more information, contact Katherine Cowan: katherine@katherinecowan.net.

Ear, nose and throat

Martin Burton, President, British Society for Academic Otolaryngology, ENT UK, writes:



“Balance problems are very common. It has been estimated that nearly a third of the UK population have experienced symptoms of dizziness or imbalance by the age of 65 and that, at any particular time, a quarter of adults in the community have significant dizziness. The Ear, Nose & Throat (ENT) community decided to concentrate on ENT aspects of balance disorders for their first PSP. Specialists in ENT and audio-vestibular medicine have joined forces to establish this project. Given how common balance problems are we have been surprised how few patient support groups and associations are available for those with this distressing and debilitating symptom. We have been able to welcome those groups we have identified onto the project team but if any readers would like to hear more about this venture - and take part in it - we would be delighted if you would contact Lester Firkins at lesterfirkins@mac.com. ENT specialists treat a wide range of disorders including some cancers and, along with professional colleagues in related disciplines, we have a second PSP at an early stage of development to address uncertainties in the treatment of head and neck cancer. Once again, interested readers are invited to let Lester Firkins know if they are interested in participating in this second PSP.”

Life after Stroke in Scotland

The aim of this PSP is to identify from Scottish patient and clinical perspectives the unanswered questions about Life after Stroke, and then prioritise those that patients and clinicians agree are



the most important. The PSP was started as a result of a project funded by the Scottish Government's National Advisory Committee for Stroke (NACS). DORIS (Database Of Research In Stroke) has been awarded 3 years' funding to facilitate the establishment, within Scotland, , easy access to completed and ongoing research evidence specific to stroke rehabilitation, treatment uncertainties, evidence gaps and research priorities, and a collaborative and inclusive approach to research planning and activity. Further information about the PSP, including its protocol, is online at www.lindalliance.org/StrokeinScotlandaJLAPrioritySettingPartnership.asp.

Pressure ulcers



Pressure ulcers (also known as pressure sores, bed sores or decubitus ulcers) are painful for patients and distressing for patients and carers. While there are lots of interventions available for

their treatment and management, evidence of the effectiveness of these interventions remains limited. Most treatments for pressure ulcers (and other chronic, complex wounds) are classified as devices rather than medicinal products. This means that manufacturers are only required to demonstrate safety and fitness for purpose and, unlike medicines, devices are not automatically subject to clinical trials to assess whether they work. The evidence-base informing clinical decision making is therefore limited.



Leeds Community Healthcare

The JLA is supporting the development of a partnership of patients, carers and clinicians to identify research priorities in the prevention and management of pressure ulcers. The objective is to discover the research questions that matter most to patients, carers and clinicians. This is part of a wider programme of work in wounds, details of which are at: www.york.ac.uk/healthsciences/research/woundsprogramme.htm.

All potential partners of this PSP are being invited to a workshop on 30 November, which will offer an opportunity to share the work done so far in setting up the partnership and canvass interest and commitment. More information about this event and the partnership can be found at the new PSP website www.jlapressureulcerpartnership.co.uk. You can register your interest in the PSP directly on the site or if you prefer, contact Sally Crowe (sally@crowe-associates.co.uk) or Dr. Mary Madden (mm538@york.ac.uk)

Intensive Care Units (ICU)

Apart from a March 2009 NICE Clinical Guideline, *Rehabilitation after critical illness* from, 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 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. The first stage will be a seminar in Edinburgh on 22 October. Anyone wanting further information should contact Professor Timothy Walsh (timothy.walsh@ed.ac.uk) or Pam Ramsay (Pam.Ramsay@luht.scot.nhs.uk). Progress reports will be published in future editions of the JLA Newsletters.



A quick guide to the JLA Guidebook

The JLA has published its online Guidebook. Katherine Cowan, one of the Guidebook's authors, explains what it is about.

What is the JLA Guidebook?

The JLA Guidebook is the online guide to establishing a Priority Setting Partnership. It's a practical, plain-English, step-by-step guide which takes you through the process, from identifying treatment uncertainties and working with patients and clinicians, to working with UK DUETs, prioritising uncertainties, and presenting them to research funders. It's evidence-based and contains a wide range of practical examples of existing JLA partnerships, including the good practice, methods and materials they have developed. At the heart of the Guidebook is the JLA protocol, which guides partners through the priority setting process.

Who's it aimed at?

Patients, clinicians and potential members of future Priority Setting Partnerships. It is also relevant to researchers, funders and anyone else with an interest in research priority setting, including those who have not yet been convinced of the value of patient and clinician involvement in research priority setting.

How does it work?

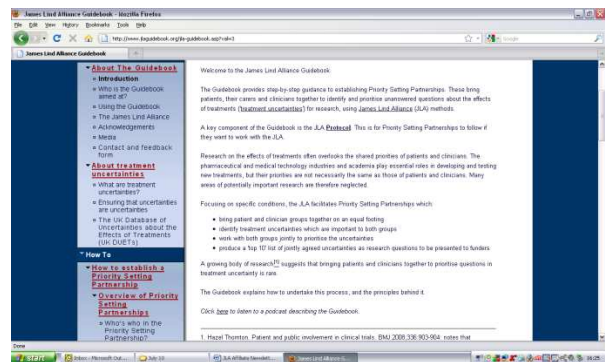
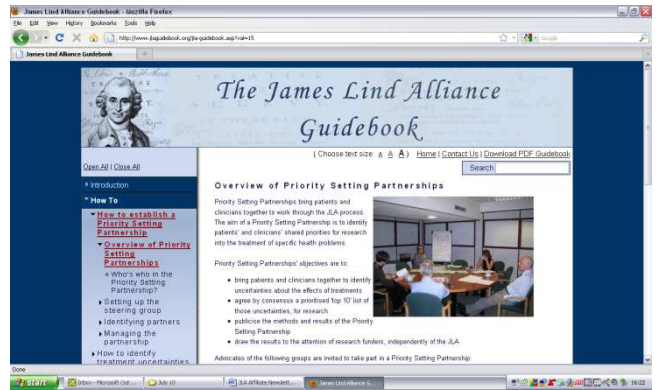
The Guidebook is an online resource. The JLA's methods are continuously evolving as we learn more from our Priority Setting Partnerships. We therefore decided to create a resource which could be easily updated to capture emerging new methods and examples of good practice. It's divided into two main sections (the 'how to' and the 'why'), which are made up of a series of short sub-sections. The content of the site is set out in sections in the left hand column of the site. There are many references to useful literature and websites, as well as a large number of documents and other materials from JLA Partnerships which you can download. It's all free of charge and we welcome your feedback.

Where is it?

Go to www.JLAguidebook.org. While you're there, you can also download a PDF version to print out.

Where can I find out more?

At www.JLAguidebook.org. Or listen to this podcast from the Cochrane Collaboration: www.cochrane.org/podcasts/international-clinical-trials-day-2010/james-lind-alliance-and-its-guidebook





RECENT EVENTS

Does industry listen to patients, and if so, why?

The report of this invitation-only think tank, hosted by the JLA, the Association of Medical Research Charities (AMRC) and National Voices, is now available to download from the JLA website. The guiding principle for the meeting was: “notwithstanding the tensions that can exist between the two sectors, there is massive potential for mutual benefit if charities and/or patient groups and industry work together.” The event thus asked how listening to and working with patients can become a vital part of the business model for the pharmaceutical industry in developing new treatments and therapies. The report is online at www.lindalliance.org/JamesLindAllianceReports.asp.

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



The report of this event is in the final stages of preparation and printing. Further details to follow in the next Newsletter.

INVOLVE

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 (right) will be speaking at Edinburgh University's intensive care summer school, which takes place from 6 to 9 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.



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



IN PRINT



Elwyn G et al. *Identifying and prioritizing uncertainties: patient and clinician engagement in the identification of research questions.* **Journal of Evaluation in Clinical Practice**, May 2010. Explores the JLA priority setting process, with reference to the Asthma Priority Setting Partnership (formerly known as the Working Partnership).

Petit-Zeman S. *Giving people what they want.* **Prospect**, July 2010. Explores how asking patients can help identify which treatments work best. Describes the JLA approach.



Cowan K. *The James Lind Alliance: tackling treatment uncertainties together.* **Journal of Ambulatory Care Management**, July/September 2010. An overview of how the JLA involves patients.



The JLA **Guidebook** has been featured in the following publications:

- *Nature Medicine*
- *Times Online Eureka Blog*
- *Cochrane Collaboration News*

Links to these as they become available can be found at www.JLAGuidebook.org – go to Introduction > About the Guidebook > Media.

ON THE WEB

Stay up-to-date with our work at 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.

A new section of the website has been created to highlight how the JLA is developing methods to ‘harvest’ treatment uncertainties, and then prioritise them. Go to www.lindalliance.org/JLA_Method.asp to find out more.

CURRENT AFFILIATES

The JLA currently has almost 200 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 www.lindalliance.org/Affiliate_application_online.asp.



One of the first organisations to affiliate to the JLA was the Insulin Dependent Diabetes Trust (IDDT). The IDDT formed in 1994 as a direct result of patient experiences of adverse effect with genetically engineered 'human' insulin having being widely ignored or dismissed. Founder, Jenny Hirst (right), explains:



“Amidst pharmaceutical companies’ threats of the withdrawal of animal insulins, a GP and I formed IDDT to take action to maintain supplies of animal insulins; to seek recognition for the adverse experiences that some people experienced; and to support people to be assertive in their choice to return to animal insulin. IDDT came to realise there was a lack of evidence of benefit of human insulin and no research comparing mortality and the death rates or quality of life associated with different kinds of insulin – vital issues to people with diabetes. So when I was asked to join the initial meeting of the JLA, the principles were very close to my heart as, in its small way, IDDT is a partnership between clinicians and patients working together on issues that were important to them both. In doing so, we identified gaps in research in the treatment of insulin-requiring diabetes. I have seen the JLA go through difficult and frustrating times but I am delighted that it is now a successful organisation and that its principles are being recognised as an essential part of the research process.”

For more information, go to www.iddt.org.

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 our website: www.lindalliance.org. In the Publications section you will find a downloadable bibliography, along with an archive of 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, September 2010.

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