The James Lind Alliance

Affiliates Newsletter – January 2010

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MESSAGE FROM THE CHAIR

Dear Colleague,

Happy New Year and welcome to the first JLA Affiliates Newsletter of 2010.

Following the excellent news of the continuation of our funding from NIHR and MRC, everyone at the JLA is looking forward to another busy and exciting year.

We are working flat-out to be ready to release our on-line Guidebook in the spring. This should be a very helpful resource, enabling more priority setting partnerships (PSPs) to progress under our guidance. It will also be a source of reference for those interested in this whole field and wanting to see where we are gaining our experience – the "evidence" upon which our guidance is being developed.

Our PSPs continue to develop, each one different from the last. As a "patient/carer" myself I am intrigued that the main challenge for two of our groups is finding enough clinicians to match the number of patients already involved. For the JLA, patient, public and clinician involvement (PPCI) is at the heart of what we do. So this means ensuring we find new and effective ways to describe the purpose and benefits of a PSP which will appeal to all parties.

Finally, we are delighted that the Urinary Incontinence PSP's work has resulted in moving even closer to securing funding for the research of a number of its prioritised treatment uncertainties - a real measure of success which will be shared more widely as it comes to fruition.

Thanks, as always, for your support.

Lester Firkins

Lester Firkins, Chair, James Lind Alliance

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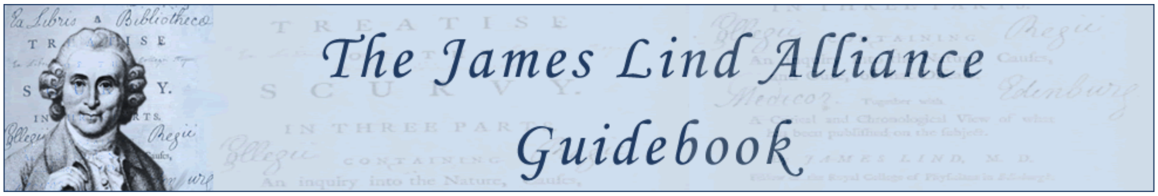
NEWS

The JLA Guidebook – coming soon

A major focus within the JLA over the past year has been the development of guidance on the priority setting process. This year will see the launch of our online resource containing evidence-based guidance on: setting up a Priority Setting Partnership; gathering patients' and clinicians' treatment uncertainties; working with the UK Database of Uncertainties about the Effects of Treatments (UK DUETs); interim and final priority setting; and taking priorities to research funders. It will also contain the JLA Protocol, which partners will be expected to sign up to in order to commit to the JLA process. This is an exciting development for the JLA. We hope it will promote the value of patient and clinician involvement in research priority setting, and become a place where good practice and innovation can be widely shared. The resource is currently being tested by a variety of different stakeholders. We will update you on its launch in the spring.



healthtalkonline.org
youthhealthtalk.org

Healthtalkonline.org – schizophrenia

Healthtalkonline.org is a website about people's real life experiences of health and lifestyle. On the site you can watch, listen and read other people's experiences. Many people who have experienced psychosis, or have been diagnosed with schizophrenia, can feel anxious or concerned about what has happened to them, and how it will affect their lives. Families, too, may have questions about what it means, how their relative must be feeling, and what they can do to help. Healthtalkonline.org is developing a new section and is looking for people to help them. If you are aged 16 or above, have experienced psychosis and would like to share your experiences through a confidential interview or a video, please get in touch. If you change your mind or decide it's not for you, you can withdraw from the process at any time. For more information, please contact Laura Griffith: Laura.Griffith@dphpc.ox.ac.uk, 01865 617767 or 07792 096719.

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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).

Vitiligo

The Vitiligo Priority Setting Partnership is part of a wider initiative, Setting Priorities and Reducing Uncertainties for people with Skin Disease (SPRUSD).

An exercise to gather patients' and clinicians' treatment uncertainties was extraordinarily successful and yielded 1170 submissions. These have been checked, and just over 100 will be entered into UK DUETs as true uncertainties – many of these combine original duplicated submissions. Partners have worked hard to develop an innovative new web-based voting tool for interim priority setting. This is live and can be seen at www.vitiligostudy.org.uk. The final priority setting meeting is scheduled to take place on 25 March.

Prostate cancer

The Prostate Cancer PSP continues to move forward under the enthusiastic leadership of the Steering Group. Treatment uncertainties have been gathered from patients and clinicians and are now being analysed and sorted ready for input into UK DUETs. One of the challenges for this partnership has been engagement with clinicians. The essence of the JLA is *collaboration* between patients *and* clinicians to identify their shared priorities. The steering group is therefore focusing its efforts on this to ensure that, when we reach the final priority setting stages, the partnership is equitable, representative and workable. Any clinician interested, but not yet involved, should contact Lester Firkins urgently (lesterfirkins@mac.com).

Type 1 diabetes

A type 1 diabetes module has been established on UK DUETs and this includes uncertainties gathered at a JLA exploratory workshop last year. These uncertainties are also now listed on NHS Evidence – Diabetes (www.library.nhs.uk/diabetes). Work to gather further treatment uncertainties for type 1 diabetes from patients and clinicians is now underway. An online survey tool is being designed and will be launched this spring.

The Insulin Dependent Diabetes Trust (IDDT) has contributed funds to support this work and all other partners will contribute their time and expertise to help this exercise be a success.

www.iddtinternational.org

For more information, please contact Patricia Atkinson: patkinson@lindalliance.org.

Schizophrenia

The Schizophrenia Priority Setting Partnership is in the process of updating the schizophrenia module in UK DUETs. In addition to the 153 uncertainties which make up the module, 50 new Cochrane reviews have been identified, as well as 13 protocols for reviews in preparation. This work is expected to be completed by the end of January and the steering group will then be identifying and inviting patient and clinician groups to join the Partnership and participate in the priority setting process. For further information please contact Katherine Cowan: katherine@katherinecowan.net.

Urinary incontinence

Having started its work in 2007, the JLA PSP on Urinary incontinence was formally wound up in 2009. However, although the identification and prioritisation work of the partnership came to an end, the dissemination of its findings has continued. From the start, dissemination was considered to be a crucial activity for the partnership. The methods and final prioritised list of research questions have been published in *Neurourology and Neurodynamics*, in a JLA report, in *Nursing Times* and *Urology News*. In October last year, the results of the PSP were presented at the Cochrane Colloquium in Singapore. They have also been reported to funding agencies with the dual aims of acting as a catalyst for research design and funding applications, and of informing funding decisions.

Brian Buckley at the final priority setting meeting

"This engagement with the research community has paid off," says Brian Buckley, Chair of the Bladder & Bowel Foundation, and a key player in the PSP, comments. "At this stage no details can be published because research funding applications are generally confidential until funding is secured. However, we are aware of four funding applications having been made that address all or part of three of the top ten prioritised research questions. A new systematic review has been proposed that will address a fourth. And a collaboration of researchers is already looking at how a study might best be designed to address a fifth."

The JLA congratulates the Urinary Incontinence PSP on their excellent progress and looks forward to sharing further updates in future Newsletters.

Work in progress

Further PSPs are in development and are on track to start working with the JLA. These include: ear, nose and throat (ENT); stroke in Scotland; Tourette syndrome; and Intensive Care Units. Anyone with an interest in any of these fields should contact Lester Firkins (lesterfirkins@mac.com).

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RESEARCH

The JLA is working to develop a body of research to inform patient and clinician 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 secretariat (patkinson@lindalliance.org).

Priority setting – community of interest

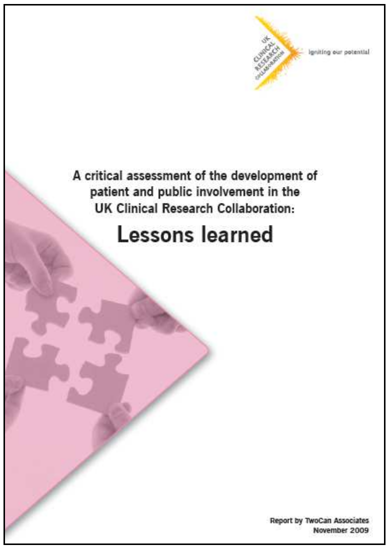
The JLA and the Cochrane Collaboration are interested in establishing a 'community of interest' in research priority setting. Initial contacts suggest that many JLA affiliates and other networks are interested in contributing and hearing about different approaches and experiences of priority setting in research. More information will follow in the next Newsletter.

Lessons learned: a critical assessment of the development of patient and public involvement in the UK Clinical Research Collaboration

This report was researched and written by TwoCan Associates, who were commissioned by the UKCRC's Board Subgroup for (PPI) Patient and Public Involvement (on which the JLA is represented). The aim of the assessment was primarily to identify lessons learned of relevance to people with responsibility for taking forward PPI in research organisations. The assessment focused on the work that was undertaken to promote and support PPI both internally within the UKCRC and externally amongst its partner organisations. It examines the challenges and the opportunities for successful and productive PPI.

A number of the lessons for people with responsibility for taking forward PPI in research organisations are summarised below:

- make PPI a priority early on
- identify clear aims and develop a shared understanding of PPI
- ensure you have dedicated resources and the right staff as early as possible
- develop a strategy that has broad ownership, but also directs and coordinates action
- ensure that all PPI-related activity is visible and adds value to other activities
- consider how you will measure any impact of PPI when you are at the planning stages
- ensure you have senior level commitment to PPI
- develop positive strategies to challenge skeptics, including demonstrating how PPI can help research organisations achieve their goals



UK CLINICAL RESEARCH COLLABORATION
igniting our potential

A critical assessment of the development of
patient and public involvement in the
UK Clinical Research Collaboration:

Lessons learned

Report by TwoCan Associates
November 2009

For further information go to: www.ukcrc.org/patientsandpublic/ppi/understandingppi.

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Field trip

In autumn 2009, Sally Crowe, Chair of the JLA's Monitoring and Information Group, visited ZonMw (The Netherlands Organisation for Health Research and Development - www.zonmw.nl) in the Hague. The JLA was asked to share its learning from its work with the UK Database of Uncertainties in the Effects of Treatments (UK DUETs) and the shared priority setting of these uncertainties with interested clinicians, researchers and patients and carers. The JLA then participated in a meeting with health policy makers to discuss the feasibility of setting up a version of UK DUETs in the Netherlands. This work is being developed further within ZonMw. The JLA has longstanding links with ZonMw and the Athena Institute, where similar work in prioritisation has been ongoing for several years. We were delighted to have been invited to collaborate and share experiences.

ZonMw

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RECENT EVENTS

JLA, Association of Medical Research Charities (AMRC) and National Voices joint event

This invitation-only think tank - *Does industry listen to patients, and if so, why?* - took place on 9 October 2009. A draft report from the day is now being used by the JLA and the AMRC to identify next steps from among the many possible avenues identified during the think tank. There was clear interest in how industry can best heed patient voices, and much discussion about how best to achieve this. A meeting soon afterwards involving JLA, AMRC and members of Oxford's Green Templeton College, which is launching some pilot projects under the banner of the proposed Health Experiences Institute, may also help us to progress this work. We will update JLA Affiliates through future newsletters.

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FORTHCOMING EVENTS

In February, the JLA, the AMRC and INVOLVE will be hosting an event entitled *Building on Success – opportunities to progress patient and public involvement in research prioritisation and commissioning*. It is an opportunity to draw on the lessons learned from the patient and public involvement (PPI) work of the recently disbanded UK Clinical Research Collaboration.

The aim of the event is to understand how to improve the impact of PPI in research prioritisation and commissioning. Facilitated discussions will focus on:

- routinely collecting information about PPI in research prioritisation and commissioning
- creating incentives for researchers to research areas prioritised through processes where patients/public have been included
- increasing the role and value of PPI in established peer review processes for commissioning research
- the value of involving the public in discussions and decisions about competing research needs and distributing funding

Attendance is by invitation only, and the event is full, but a full report of the meeting's outcomes will be published on the JLA website. An update will follow in the next newsletter.

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

Buckley BS, Grant AM, Tincello DG, Wagg AS, Firkins L. Reaching a consensus on research priorities in urinary incontinence. *Nursing Times*, online publication. December 2009.

Abstract:

Gaps in the evidence base in healthcare are common, and this is also the case for the management of urinary incontinence.The James Lind Alliance helped patients and clinicians to work together to identify and then prioritise gaps in the evidence base for managing this condition, producing a list of 10 research priorities. This article outlines the process involved in reaching this consensus.

NURSING times.net

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ON THE WEB

Stay up-to-date with our work at **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 186 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

One of our recent Affiliates is the Prostate Cancer Support Federation, an umbrella body set up to provide a focus for the activities of the numerous patient-led support groups across the country, and a key member of the JLA Prostate Cancer Priority Setting Partnership. The Federation's Chairman, Sandy Tyndale-Biscoe welcomes the PSP as a much needed opportunity for patients' voices to be heard by those planning and funding research.

"Prostate cancer, because so little is known about it, is almost unique amongst cancers in the extent to which patients have to make decisions about their treatment," he says. "It is only right that they should have a say in how research money is spent."


Sandy Tyndale-Biscoe

Prostate Cancer Support Federation

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

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In memoriam

The JLA was very sad to learn of the recent death of Jenny Henderson from the MS Trust. Jenny was an active participant in the Urinary Incontinence Priority Setting Partnership and made a huge contribution to its work. The JLA is very grateful for this. We send our best wishes to Jenny's family, friends and colleagues.

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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 April 2010.

Patricia Atkinson
James Lind Alliance
Summertown Pavilion
Middle Way
Oxford OX2 7LG.

patkinson@lindalliance.org

www.lindalliance.org

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