



Affiliates Newsletter – January 2009

MESSAGE FROM THE CHAIR

Dear Colleague,

Firstly, Happy New Year and welcome to the new-look newsletter – which we hope to now produce on a quarterly basis.

Our aim is to give you a flavour of all that we are working on as we pursue our main objective of helping patients and clinicians work together to identify and prioritise the treatment uncertainties that they feel are most important.

This work is only possible through the continued enthusiastic support from the National Institute for Health Research and Medical Research Council not just by way of funding but also by their active participation and encouragement.

If you have any comments or suggestions of what you think we could do more or less of then please do let me know – and also if there is anything that we can do to help your own aims and objectives.

Whilst we are only a very small team we do try and “punch above our weight”, and are always on the look-out for new opportunities to get our important message across.

Thank you so much for your continued support,

Lester Firkins



MEET THE TEAM

The JLA comprises a mix of lay people, healthcare and clinical research professionals, and experts in Patient and Public Involvement. A Strategy & Development Group, chaired by Lester Firkins, determines the overall direction of the JLA. The day to day operation of the JLA is managed by a Monitoring & Implementation Group chaired by Sally Crowe, and supported by Lester Firkins, Katherine Cowan and Patricia Atkinson.

Lester Firkins

Lester is the Chair of the JLA, and also chairs its Strategy & Development Group. A former banker, in 2001 Lester's eldest son died from vCJD, and after being invited to Co-Chair the MRC Clinical Trial he was drawn into world of patient and carer involvement in research.



Sally Crowe

Sally chairs the Monitoring & Implementation Group and manages the JLA's programme of seminars. She supports several Priority Setting Partnerships, and oversees the development of the partnerships' priority setting methods. She has also managed two key projects that are contributing to the evidence base of shared priority setting in clinical research.



Katherine Cowan

Katherine has been working with the JLA since March 2008. She was involved documenting the process of the Urinary Incontinence Priority Setting Partnership, and coordinates the evaluation of the other Priority Setting Partnerships. She manages the Annual Report production and is leading on the development of a JLA priority setting protocol.



Patricia Atkinson

Patricia is the Administrator of the James Lind Initiative, which was formed to encourage wider acknowledgement of uncertainties about the effects of treatments. A large part of her role is to support projects like the JLA and the Database of Uncertainties about the Effects of Treatments (DUETs). Patricia is the main point of contact for the JLA.



The JLA is guided by the **Strategy & Development Group** which meets three times a year. Members include representatives from (among others) the National Institute for Health Research (NIHR), the Medical Research Council (MRC), the National Institute for Health and Clinical Excellence (NICE), INVOLVE, the Association of Medical Research Charities (AMRC), the NIHR Health Technology Assessment Programme, the UK Clinical Research Collaboration and the UK Clinical Research Network, the Royal Society of Medicine (RSM), and the Database of Uncertainties about the Effects of Treatments (DUETs).

The **Monitoring & Implementation Group** manages the activities of the JLA and is accountable for its deliverables. It meets monthly, usually in Oxford. The Group is Chaired by Sally Crowe. Other members are Glyn Elwyn (Cardiff University), Mark Fenton (DUETs), Sophie Petit-Zeman (AMRC), John Scadding (RSM), Maryrose Tarpey (INVOLVE), and Lester Firkins, Katherine Cowan and Patricia Atkinson (JLA).

NEWS

The JLA **Annual Report 2007/08** summarises our work so far in involving patients and clinicians in identifying research priorities through our priority setting partnerships, as well as reporting on our research and awareness-raising and partnership working. Major achievements for the year include:

- concluding our first Priority Setting Partnership, for Asthma
- the successful submission of a bid for independent research commissioned by the National Institute for Health Research (www.nihr.ac.uk) under the Programme Grants for Applied Research
- the further growth of the JLA profile, through research, seminars, articles, reports and presentations

The Annual Report will shortly be available to download at www.lindalliance.org.



The **Asthma Priority Setting Partnership** took us on a journey from 850 asthma treatment ‘uncertainties’ submitted by patients, clinicians, carers and researchers, 126 of which were verified as real uncertainties. All 126 verified uncertainties have been published in the Database of Uncertainties about the Effects of Treatments (DUETs). These were then processed into a top 10 list of research priorities agreed by patients, carers and clinicians. Stephen Holgate, MRC Clinical Professor at the University of Southampton, said of the process:

“The JLA priority setting exercise in asthma has identified a series of research questions that certainly would not have been identified otherwise. Of particular interest is the selection of drug-related side effects, breathing exercises in treatment and the different ways to treat severe asthma. I am delighted that the HTA is taking forward several of these to work them up into researchable questions with strong justification.”

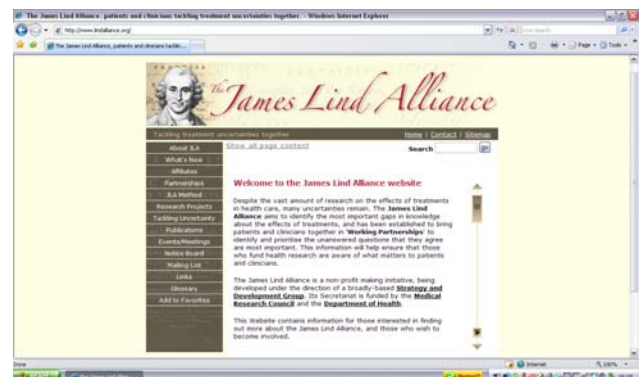
The **Urinary Incontinence Priority Setting Partnership** completed its task in November, at a meeting which saw clinicians and patient representatives agree a top 10 list of shared priorities for research on the treatment of urinary incontinence. See below for more detail on this exciting project.



DUETs has a new home - www.library.nhs.uk/duets. The Database of Uncertainties about the Effects of Treatments (DUETs) was established in the UK to publish uncertainties that cannot currently be answered by referring to reliable up-to-date systematic reviews of existing research evidence. It has now become part of the National Library for Health, which will, in turn, soon become an element of NHS Evidence, and accessible through NHS Choices (www.nhs.uk).

The JLA website

(www.lindalliance.org) has been redesigned to make it easier to access and navigate. The site includes details of all of our work, information about JLA events and meetings and research updates, as well as links to our Affiliates and an interactive notice board. We encourage our Affiliates to visit the new website and give us their feedback. Any comments or suggestions can be sent to Patricia (patkinson@lindalliance.org).





PARTNERSHIPS UPDATE

The JLA Priority Setting Partnerships (formerly known as Working Partnerships) are comprised of patients, carers and clinicians, working together to identify treatment uncertainties, and to prioritise those uncertainties for research. On the basis of a forthcoming review of evidence from around the world (more details to follow in the next Newsletter), the JLA process is groundbreaking and appears to be unique. Groups or consortia interested in forming a JLA Priority Setting Partnership should initially contact Patricia Atkinson (patkinson@lindalliance.org).

Urinary Incontinence

The Urinary Incontinence Priority Setting Partnership came together in October 2006, when Brian Buckley (Bladder & Bowel Foundation) and Adrian Grant (Cochrane Collaboration) approached the JLA. A partnership of 21 organisations was formed and worked hard to establish a list of 226 treatment uncertainties, which were then taken through a rigorous process of prioritisation. First an interim shortlist of 29 priorities was agreed, then partners participated in a final priority setting workshop to agree a shared top 10 research priorities to present to researchers and funders. A detailed paper on the entire process together with full details of the selected uncertainties will be available shortly.

Vitiligo

The JLA is a partner in a new project commissioned by the National Institute for Health Research under the Programme Grants for Applied Research, called **Setting Priorities and Uncertainties for People with Skin Disease, or SPRUSD** for short. It is being co-ordinated by the Centre for Evidence Based Dermatology in Nottingham. The Centre incorporates the NLH Skin Disorders Specialist Library, the Cochrane Skin Group and the UK Dermatology Clinical Trials Network (UKDCTN). The new project is ambitious, with several streams of work, including eczema and vitiligo, and it will last 5 years. As part of the project, the Vitiligo Society and its members will identify areas of uncertainty about treating this common skin disorder, in which patches of skin lose their colour. These uncertainties will all be published in DUETs, along with uncertainties from other sources. The JLA will then facilitate a priority setting process that will include the Vitiligo Society and its members and health professionals and researchers, to agree a top ten list of research questions. We will keep Affiliates posted as this process evolves. For further information please contact Sally Crowe (sally@crowe-associates.co.uk).

Eczema will start its process later in 2009. The key lay partner for this work will be the Eczema Society.

Prostate Cancer

The JLA is at an early stage of discussions with members of the Prostate Cancer Charter for Action with a view to building a Priority Setting Partnership.

Type 1 Diabetes

We are also planning a workshop in Spring 2009 to explore harvesting and prioritising uncertainties about treatment of Type 1 Diabetes. Please contact Patricia Atkinson (patkinson@lindalliance.org) for further information.

Our commitment to continual improvement

The JLA's process of harvesting and prioritising treatment uncertainties of importance both to clinicians and to patients appears to be unique. As such, we are continually looking to learn as our work evolves and to fine-tune our processes. To enable us to do this, we have developed an online facility to capture feedback from priority setting partners and evaluate our facilitation. The evaluation is confidential and anonymous. The first evaluation, of the Urinary Incontinence Priority Setting Partnership, is still being analysed. We will share the findings with you in our next update for JLA Affiliates.

RESEARCH

One of the JLA's strategic aims is to develop a body of research to inform patient involvement in research priority-setting. We have commissioned a range of research.

Epilepsy patients' unanswered questions

The JLA and DUETs, in collaboration with the University of Wales Swansea and the University Hospital of Wales, commissioned PatientView to carry out a survey of epilepsy patient groups. The aim was to identify questions that doctors cannot currently answer, but which epilepsy patients have about their treatment. Thirty five patient organisations took part in the survey, and the findings will shortly be available on the JLA website. This survey is an important step in providing epilepsy patients and carers a more audible voice in medical research. The results will feed into a forthcoming DUETs module of treatment uncertainties.

Patients' and clinicians' research priorities

The JLA has funded the Social Science Research Unit (SSRU) to examine the evidence base on user involvement in shared research priority setting. Building on existing bibliographies, the SSRU systematically reviewed abstracts of reports of priority setting exercises which involved service users and clinicians. A report is being produced which describes (i) who has been involved in setting research agendas; (ii) the ways in which service users and clinicians have been involved in setting research agendas; and (iii) what types of research questions they have identified as important. The project team are currently finalising a paper to share these results.



RECENT EVENTS

The past few months have seen the JLA busy raising its profile as a key player in patient involvement. Working in partnership with the Social Science Research Unit and the Royal College of Nursing Institute, the JLA organised and hosted a conference in November 2008, entitled **Outcomes in clinical research – whose responsibility?**. The day was attended by over 140 researchers, patient groups, clinicians, charities, and other health research groups, with the aim of promoting debate about the role of these constituencies in determining relevant outcomes to be measured in clinical research, and to distinguish between Patient Reported Outcomes and Patient Important Outcomes. The event was chaired by Sir Iain Chalmers and speakers included Dr Kirstie Haywood (Royal College of Nursing Research Institute), Prof Sandy Oliver (Social Science Research Unit), Dr Diana Rose (Institute of Psychiatry), Prof Suzanne Skevington (Bath University), and Alex Wyke (Patient View).

Discussion sessions covered 12 distinct topics, including children's outcomes in research, back pain, mental health, pregnancy and childbirth, and multiple sclerosis. The meeting provided a successful forum for debating, learning, sharing good practice and networking. Most of the presentations will be available on the JLA website (www.lindalliance.org) and a report from the discussion groups will be on the website in February.

INVOLVE

The JLA took part in the bi-annual INVOLVE conference in November 2008, with an information stand and a well attended workshop addressing the issues of making patients' and carers' voices count in research agendas. A presentation by TwoCan Associates of a project commissioned by the JLA to map patient involvement in shared priority setting in UK funding and research organisations provoked a lively debate. As one participant noted: when working with the JLA, *"all you can lose is your inhibition!"*

NICE 2008 10th anniversary conference

In December 2008, Lester Firkins and Brian Buckley presented the findings of the JLA Urinary Incontinence Priority Setting Partnership at the NICE conference. The topic was very well received and useful connections were made.

Round up

The JLA has also presented recently at: the Prostate Cancer Action Charter, the US Cochrane Group in Baltimore, USA, the Collaborative Patient Involvement Group, and *Who's life is it anyway – hot topics in clinical trials*, hosted by the Edinburgh Clinical Trials Unit.



FORTHCOMING EVENTS

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

- Patient Reported Outcome Measures Healthcare Conference, 22 January
- Annual meeting of UK contributors to the Cochrane Collaboration, March
- Patient Information Forum, March
- Wellcome Trust Edinburgh Clinical Research Facility Open Day, March
- Nurses and Allied Health in Critical Care, Edinburgh, March

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

IN PRINT

The JLA has featured in a number of publications in the past few months.

Lester Firkins. *The problem in setting research priorities: a layman's experience*, **BMJ** 2008;337:a212: stresses the need for patient and carer involvement in research as standard practice, and how lack of academic collaboration can compromise patients' interests.

Brian Buckley. *Identifying uncertainties to prioritise research*. **Nursing Times** 2008;104:18,38-39: describes the JLA's partnership work to identify treatment uncertainties in the care of people with urinary incontinence, and to prioritise these to influence and inform publicly funded research.

Hazel Thornton. *Patient and public involvement in clinical trials*. **BMJ** 2008;336:903-904: notes that encouragement is still needed to promote institutional collaboration and avoid duplication of effort in Patient and Public Involvement in clinical trials. Cites the JLA as a rare example of lay people and health professionals prioritising research questions together.



CURRENT AFFILIATES

The JLA currently has 166 Affiliates, most of which 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.

KEEP IN TOUCH!

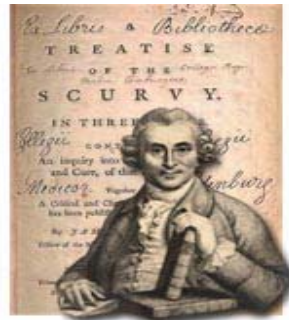
We hope you have enjoyed the new JLA Affiliates' Newsletter. Please contact us with any news, feedback, updates or information you would like to see featured in the next edition, in April.

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All the best for 2009, from the James Lind Alliance.

