



Affiliates Newsletter – October 2009

MESSAGE FROM THE CHAIR

Dear Colleague,

Welcome to the fourth and final Affiliates Newsletter of 2009.

I am delighted to report that the JLA has received indicative confirmation that funding will continue for a further three years – until March 2013. Our funders, NIHR and MRC, are pleased with our direction and focus and so are happy to stand with us for this further period. There will be much expected of us, and we will start planning the detailed activities for presentation to our Strategy and Development Committee in early 2010.

Within the newsletter you will see that the Urinary Incontinence Priority Setting Partnership has concluded with excellent outcomes – and yet more Partnerships are being added to the list of work in progress.

We continue to work on our Guidebook for publication in spring 2010. This will be the bedrock of how we help patients and clinicians to work together in a very practical way.

Thank you for continuing your support and interest. We have been fortunate to receive positive feedback about these newsletters – so please let that continue (if merited), and equally please let us know if you think we could do things differently or indeed better.

Lester Firkins, Chair, James Lind Alliance



NEWS



New epilepsy module on UK DUETs

Work has been undertaken by the Wales Epilepsy Research Network to identify patients' and clinicians' uncertainties about treatments for epilepsy. This will create a new module in the UK Database of Uncertainties about the Effects of Treatments (UK DUETs). An exercise to gather and rank patients and clinicians' uncertainties yielded some interesting results: patient questions were more likely to focus on practical considerations, such as how to minimise drug side effects. Professionals' questions were also practical but clustered around 'difficult consultations' such as prescribing in pregnancy. Surprisingly, professionals rated 'consideration of the patient as an individual' as a more important research theme than patients did. The most important shared priorities focused on uncertainties about how to avoid cognitive problems and problems in pregnancy with epilepsy. The first 60 uncertainties have been screened to check they are justified. These have been published online at UK DUETs, and the rest will follow shortly. www.library.nhs.uk/DUETs.



The Scottish School of Primary Care

UK Primary Care Research Portfolio Review – call for panel members for prioritisation exercise

The UK Primary Care Research Portfolio Review group is looking for panel members to prioritise primary care research issues across the full spectrum of clinical areas. The breadth and depth of primary care research have recently been summarised in a review of research registered on the UK Clinical Research Network database (www.sspc.ac.uk/spcrn/reports.htm). The report has identified areas of strength and important gaps. The next step is to decide, by a Delphi process of voting in stages, which of the gaps to prioritise for research. This will be conducted using email. For further information, or to take part as a panel member, please contact Laura Wilkie, SSPC, Mackenzie Building, Dundee DD2 4BF. l.wilkie@cpse.dundee.ac.uk



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).

Urinary Incontinence

The JLA Urinary Incontinence Priority Setting Partnership's top ten priorities have now been published in the *Neurourology and Urodynamics* journal. Separate articles relating to that publication will appear in *Urology News* and *Nursing Times* before the end of the year. The number one uncertainty for both patients and clinicians was: "What are the optimal pelvic floor muscle training protocols for the treatment of different patterns of urinary incontinence?"

Neurourology
of
Urodynamics



Brian Buckley (Bladder & Bowel Foundation) and Adrian Grant (Cochrane Collaboration) have been instrumental in driving this initiative forward. Referring to the unique nature of the JLA approach, Adrian recently noted:

"I think the reassuring thing for me was, firstly from a Cochrane perspective, how many of the top ten were relevant – they needed new or updated reviews - and how few came from the research recommendations of existing Cochrane reviews. Secondly, more generally, the priorities would have been substantially different if the process had been done by professional or patient groups working on their own."

The top ten priorities have recently been reviewed by the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) programme. The great news is that almost all of them potentially fall within the remit of the HTA programme and eight of the top ten are now being submitted to the Programme to be considered for prioritisation by the HTA Advisory Panels in January. This is encouraging, not only for the treatment of urinary incontinence, but also for other JLA Priority Setting Partnerships. The JLA is hugely appreciative of the HTA programme's continued support and encouragement.



Prostate Cancer

The Prostate Cancer Priority Setting Partnership is making good progress. It has almost finished collecting treatment uncertainties from patients and clinicians. A survey has been hosted on the website of the Prostate Cancer Research Foundation, which is being downloaded and sent back by men affected by prostate cancer, the people who care for them and the clinicians who treat them. There are potentially 90 organisations involved, making this the largest JLA Priority Setting Partnership to date.



Vitiligo

The Vitiligo Priority Setting Partnership is part of a wider initiative, Setting Priorities and Reducing Uncertainties for people with Skin Disease (SPRUSD). After a four month period of consultation on uncertainties, the survey is now closed. In total, 1170 uncertainties were submitted. Two thirds came from patients, one third from clinicians. Over 50 per cent of the questions are related to treatment.

The SPRUSD group has developed 27 themes from these questions. Due to the large number of uncertainties, partners are developing a web-based voting tool for interim priority setting. This will go live later this year, with a view to carrying out final priority setting by February 2010.

Featured in this newsletter is an article by Maxine Whitton, Patron of the Vitiligo Society, which highlights the importance of this initiative.



Type 1 diabetes

Following an exploratory workshop in June 2009, several key partners have emerged to address treatment uncertainties in type 1 diabetes. These comprise the National Institute for Health Research Clinical Research Network, Diabetes Research Network, Juvenile Diabetes Research Foundation, NHS Evidence –diabetes and the Insulin Dependent Diabetes Trust (IDDT). Together with the JLA and UK DUETs they will be planning a consultation on treatment uncertainties in type 1 diabetes, with a view to prioritising these. Other potential partners have been identified, and if you want to be part of this work please contact the JLA (patkinson@lindalliance.org).

Schizophrenia

The newest partnership to be formed is the Schizophrenia Priority Setting Partnership. Schizophrenia is a mental illness that affects about one in a hundred people at some point in life. Approximately 30 to 40 per cent of people with schizophrenia attempt suicide at some time, with one in ten eventually killing themselves. An exercise funded by the Welsh Office of Research and Development was carried out to identify patients' and clinicians' uncertainties about schizophrenia treatments. Of these uncertainties, 153 now make up the schizophrenia module in UK DUETs. A Priority Setting Partnership will be brought together to prioritise these uncertainties into a top ten list of patients' and clinicians' shared priorities for research. The steering group is currently being assembled and so far includes clinical representatives from the Universities of Swansea and Nottingham, and patient representatives from the Institute of Psychiatry, Rethink and Hafal, the principal organisation in Wales working with individuals recovering from severe mental illness and their families. For further information please contact Katherine Cowan: katherine@katherinecowan.net.

Wound management

Members of the Wounds Group, from the Department of Health Sciences at the University of York met with the JLA and UK DUETs in September, to explore gathering treatment uncertainties as part of the National Institute for Health Research Grant Programme. Part of the programme will be research that summarises the existing evidence of which wound treatments are the most effective, and find out which aspects of wound treatments and services are most important to patients, carers and NHS staff.

Work in progress

Several other potential Priority Setting Partnerships may emerge next year. Early discussions are taking place to explore whether or not the JLA is the right vehicle to help them. These include: ear, nose and throat; Tourette's syndrome; and intensive care.

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 office (patkinson@lindalliance.org).

A systematic map of studies of patients' and clinicians' research priorities

The potential for patient and public involvement in clinical research is increasingly recognised, the rationale being that it leads to research more likely to meet the needs of patients and to influence practice than other work. In order to learn from earlier experiences of such involvement, the JLA set out to assemble a bibliography of studies about patients' and clinicians' research priorities studies. In 2008, the JLA then commissioned research to explore this literature in more detail, and to reflect on the work of the JLA in relation to this literature.

An examination of 258 studies found that there are different routes for patients and clinicians to contribute to research priorities. But clinicians are generally more involved than patients. Only 18 per cent of the studies which sought views on research consulted with patients, while eighty six per cent included clinicians. Clinicians and patients are also far more likely to work separately than collaboratively to identify research topics. This suggests that the JLA approach is extremely rare. In fact, there were only nine other accounts of clinicians and patients working together to identify and prioritise research questions. As such, the JLA is urging those involved in funding, commissioning and undertaking research to give these findings careful consideration.

A summary and full report of *A systematic map of studies of patients' and clinicians' research priorities*, written by Ruth Stewart and Sandy Oliver of the Social Science Research Unit, is now on the JLA website at:
www.lindalliance.org/Map_studies_patients_clinicians_research_priorities.asp



Sandy Oliver



Ruth Stewart



The Cochrane Systematic Review of Interventions for Vitiligo - by Maxine Whitton



Maxine Whitton

Maxine Whitton leads the National Institute for Health Research's vitiligo work stream. She has had vitiligo for more than 55 years and is a Patron of the Vitiligo Society, a key partner in the JLA Vitiligo Priority Setting Partnership.

Here she describes the importance of the Cochrane Systematic Review of interventions for vitiligo, of which she was the lead author.

What is vitiligo?

Vitiligo is a chronic, unpredictable disease which causes patchy loss of skin colour. It can affect people of all ages and from all ethnic backgrounds. Although people with vitiligo do not feel physically ill, it can cause great psychological distress, particularly for those with dark skin.

Are there any effective treatments?

There is no cure for vitiligo at present but there are treatments which can restore pigment, albeit for a limited time, in some cases. However, many GPs are either unaware that treatments can be prescribed or are reluctant to prescribe them. So people with vitiligo are sometimes told that there is nothing to be done and may leave the surgery feeling hopeless and helpless.

What is a Cochrane Systematic Review?

A Cochrane Systematic Review analyses the best possible evidence of available treatments worldwide, to find out which is the best treatment for a particular disease. The review focuses on Randomised Controlled Trials, an experiment in which two or more interventions, possibly including a control intervention, no intervention or a dummy intervention (placebo), are compared by being randomly allocated to participants. This is the gold standard for deciding whether or not a treatment works as it minimises the chance of bias

What did the Cochrane Systematic Review of interventions for vitiligo find?

The first Cochrane review of treatments for vitiligo was published in 2006. We searched the literature as far back as 1966 and only found 19 poor quality Randomised Controlled Trials. We have just completed an update due to be published in January 2010, which found twice as many new trials (38), making a total of 57 studies assessed. However, none of the trials reported long-term benefit of vitiligo treatment and it is still not possible to say what the best treatment for vitiligo is.

Where do we go from here?

The results of this review are now part of a research programme funded by the NIHR for setting priorities and reducing uncertainties for skin disease (SPRUSD). Along with the views of patients and clinicians, this review is important for prioritising which clinical trials should be embarked upon and for securing funding for them. Our final product will be a funded multi-centre trial of a specific treatment for vitiligo, which will have been identified as of most importance to patients and clinicians. The JLA prioritisation process is an excellent method of achieving this. For people with vitiligo, this offers at long last the hope of identifying an effective treatment.

www.vitiligosociety.org.uk

This report/article presents independent research commissioned by the National Institute for Health Research (NIHR). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

RECENT EVENTS

The JLA and UK DUETs were asked to share their work with colleagues in the Netherlands and Sally Crowe recently contributed to a conference there. This was part of a series of events entitled Patient Participation in Scientific Research. It consisted of a conference for clinicians, patients and researchers, followed by a smaller seminar for Dutch organisations interested in doing similar programmes to the JLA and UK DUETs.

JLA Chair, Lester Firkins, presented at the NIHR Biomedical Research Centre conference on Public Engagement in Translational Research. He also contributed to a study day in Edinburgh for the Critical Care Group.

Katherine Cowan presented the JLA process and priorities to the UKCRC's Patient and Public Involvement representatives' group.

Brian Buckley (Bladder & Bowel Foundation and JLA Strategy & Development Group member) presented the work of the Urinary Incontinence Priority Setting Partnership at the Cochrane Colloquium in Singapore as a paper in the scientific programme and in a special session relating to work funded by the Cochrane Collaboration's Prioritisation Fund.

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

On 9th October 2009, the JLA, the AMRC and National Voices co-hosted a 'think tank' exploring the extent to which the research agenda of the pharmaceutical industry can be influenced by patients and their representative organisations.



Gathering 30 delegates drawn from the two "parent" partners (AMRC and JLA) and related stakeholders, the meeting began with an informal introductory talk about the extent to which industry can/should/does/doesn't listen to patients, from Sir Iain Chalmers. We then heard three short presentations from industry speakers (Celia Brazell,

Director of Medical, Advocacy, Policy and Patient Programmes, GSK R&D; Mauricio Silva de Lima, Medical Director, Eli Lilly, UK and Ireland, and Guy Yeoman, Medical & Regulatory Affairs Director, AstraZeneca) addressing the questions: "Does industry listen to patients about research? If yes, why, and if not, might they be able to do so better?"

Dr Ralph Holme, Director of Biomedical Research at the Royal National Institute for Deaf People (RNID) spoke about "Working with industry on research for patient benefit: one charity's experience," and Mike O'Donovan told us about the work of National Voices.

The JLA has not to date worked with industry, and the event may provide food for thought as to whether such collaborations might appropriately become part of the way forward for research projects indicated by patient/clinician priority-setting partnerships.

Further details will be posted in future newsletters.

FORTHCOMING EVENTS

At the time of writing, the JLA is looking forward to being involved in the following events:

As part of World Stroke Day, 29 October 2009, the JLA's Chair, Lester Firkins, is participating in the Scottish Stroke Research Network's event 'Stroke Research: getting involved and making your voice heard'.

In April 2010, Lester Firkins will be addressing the Annual Conference of the Scottish School of Primary Care on the extent to which important gaps in knowledge about the effects of treatments remain, and how the JLA helps patients and researchers identify them and undertake the necessary research.

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

*Buckley BS, Grant AM, Tincello DG, Wagg AS, Firkins L (On behalf of the James Lind Alliance Priority Setting Partnership on Urinary Incontinence) Prioritising research: patients, carers and clinicians working together to identify and prioritise important clinical uncertainties in urinary incontinence. *Neurourology and Urodynamics* 2009 DOI: 10.1002/nau.20816.*



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.



CURRENT AFFILIATES

The JLA currently has 185 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

rethink

One of our newest Affiliates is Rethink, the leading national mental health membership charity which works to help everyone affected by severe mental illness recover a better quality of life. Founded over 30 years ago, Rethink helps over 48,000 people every year through services, support groups and by providing information on mental health problems. Rethink is a key player in the Time to Change campaign (www.time-to-change.org.uk), England's most ambitious programme to end discrimination faced by people who experience mental health problems. www.rethink.org.uk



Our latest international Affiliate is Cancer Voices NSW. Their purpose is to represent, and to act on, the needs and interests of people affected by cancer in New South Wales, Australia, and beyond, working in partnership with decision-makers.

www.cancervoices.org.uk





WANT TO FIND OUT MORE?

If you are new to the JLA or simply want to find out more about patient and public 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, in January 2010.

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