



Affiliates Newsletter – November 2011

MESSAGE FROM THE CHAIR

Dear colleague,

My heart always sinks a bit when I get the call to write my introduction to the Newsletter. I am not a journalist or an academic so I worry that my contribution will be either boring or simply lightweight. But then again, that's probably a concern many people who get involved in a Priority Setting Partnership share: what difference can I make?

But I have now seen time and again that the PSPs that truly thrive are those where people have a passion, be it clinicians or patients, even though they question the difference they can make in this massive world of research.

I have been very closely involved with the Lyme Disease PSP, and you will read how their exercise to gather uncertainties has been a resounding success in terms of the volume received, despite this being a relatively small disease area in which patients often feel misunderstood. Inspiring stuff.

So, as we all work from our own garrets in the run up to Christmas, I want to express my sincere thanks to all the people driving the PSPs for going that extra mile and hope that 2012 brings them the success they seek: research into their agreed priorities – it's not much to ask!

Finally, please do read about this Twitter lark: Katherine Cowan has done a wonderful job of raising the JLA's profile by using this tool, and it was a real asset at two major events we attended. If only I truly understood the potential it would be even better. But in following people like Margaret McCartney (@mgmtcartney), Ben Goldacre (@bengoldacre), Simon Denegri (@SDenegri), Emma Malcolm (@prostaterunning) and even Leslie Philips (@LesliePhillips_), my life is immeasurably enriched and informed.

Thanks as ever for your support and every good wish for the Christmas you seek

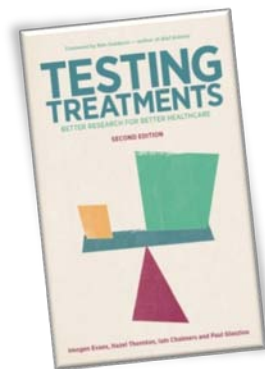
Lester Firkins, Chair, James Lind Alliance



NEWS

Testing Treatments: second edition launched

October saw the launch of the second edition of *Testing Treatments*, written by Imogen Evans, Hazel Thornton, Iain Chalmers and Paul Glasziou, with a foreword by Ben Goldacre. *Testing Treatments* makes the case for more reliable, relevant research, and urges patients and clinicians to work together to achieve this. The new edition has additional chapters explaining how screening for disease and over-regulation of research can both sometimes do more harm than good.



Iain Chalmers, Imogen Evans, Hazel Thornton, Paul Glasziou and Ben Goldacre at the launch of the second edition of *Testing Treatments*.

Testing Treatments is available in paperback and eBook formats directly from the publishers (www.pinterandmartin.com), or from Amazon, Alibris or other booksellers. In addition, the full texts of the first and second editions of the book, together with translations into other languages, are available for free download from www.testingtreatments.org.

The text of the new edition of the book is the starting point for developing *Testing Treatments Interactive*. This resource will allow more flexible searches of the text of the book and will link from the text to video

and audio resources, games, and apps to help people understand the principles and explanations covered in the book. *Testing Treatments Interactive* is being developed by Iain Chalmers, Paul Glasziou, Amanda Burls and Douglas Badenoch, and will use Web 2.0 technology to involve others in the development of the resource. Readers of the JLA Newsletter are invited to help the development team to build *Testing Treatments Interactive* by signing up for updates and submitting comments through www.testingtreatments.org.

Testing Tweetments: JLA continues its foray into Twitter

The JLA is settling into Twitter, the micro-blogging site, at www.twitter.com/LindAlliance. With each tweet, we are learning more about its potential for connections, debate and awareness-raising. If you are following us, you will hopefully have enjoyed our live tweets from the Evidence 2011 conference in London in October. We also joined in the debate with attendees of the Cochrane Colloquium in Madrid, and were pleased to get positive feedback for our presentation in both English and Spanish. We are keen to use our Twitter feed to generate interest in and discussion about patient and clinician



involvement in research priority setting. If you are aware of any interesting articles or blogs about which you think we should be tweeting, do let us know, via Twitter, or to katherine@katherinecowan.net.



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).

Life After Stroke in Scotland

For a full report on this PSP's final priority setting workshop, and resultant top 10 priorities for research, go to page 6.

Head and Neck Cancer

This PSP, led by ENT UK and Head and Neck 5000, will be gathering uncertainties until 30 November. Anyone with an interest in this area can participate in the survey at

www.surveymonkey.com/s/Head_Neck_Cancer-Research_Priority_Setting_Partnership.

Lester Firkins, Chair of this PSP, has been surprised at the initial lack of responses to the two waves of letters seeking people's uncertainties. "This is despite a great deal of effort by the patient and clinician leads and also the inclusion of video podcasts of a previous meeting which gives a huge amount of information", he said. "We all hope that this second extension of the harvesting timescale will prove fruitful." For further information about this PSP, go to

www.lindalliance.org/HeadandNeckCancerJLAPrioritySettingPartnership.asp.

Or contact Jo White at Jo@entuk.org.



Pressure Ulcers

Sally Crowe reports: "Richard Morley has started as the Programme Support Officer at the Wounds Research Group at York University, and will be supporting the day to day activity of this PSP. He brings extensive experience in partnership working and we look forward to working with him. Uncertainties are being gathered through a variety of approaches which has given the partnership a good idea of the scope of prevention



and treatment issues. A treatment and prevention uncertainty survey is in development and currently being piloted."

To keep up to date with progress, visit the PSP's website www.ilapressureulcerpartnership.co.uk. For further information on

the next stages please contact either Richard at richard.morley@york.ac.uk or Dr Mary Madden at mary.madden@york.ac.uk.

Wounds research
for patient benefit

Lyme Disease

The Lyme Disease PSP survey has now closed, following an impressive response. Following three months of promotion and awareness-raising, including a letter in the Financial Times magazine, the survey attracted 253 respondents, who between them had over 800 uncertainties about the treatment of Lyme disease. Stella Huyshe-Shires from Lyme Disease Action said, "With the huge number of





submissions, the first step is to discard those that are not true uncertainties and then group the remainder into something manageable. We hope that this PSP, as well as documenting the true uncertainties, will lay the groundwork for a fundamental shift in attitudes and a move from resistive antagonism to accepting cooperation.” For further information on this PSP, please contact Stella.Huyshe@LymeDiseaseAction.org.uk. For a personal view on living with Lyme disease, go to page 8.

Preterm Birth

The Preterm Birth PSP had its first Steering Group meeting on 14 November at the Clinical Trials Unit at Queen’s Medical Centre in Nottingham. Sally Crowe, who chairs this PSP, welcomed representatives from clinical and service users’ organisations. They shared their experience of surveying and discussed ways to identify and prioritise research uncertainties in preterm birth. Additional organisations and individuals to invite to the PSP were also suggested by the members. Seilin Uhm, who is coordinating the PSP, said “We had a very interesting discussion on the scope of our PSP. We previously limited our scope to the interventions in the delivery room and during the first hour of birth. However, all members of the Steering Group have agreed that our questions should include both antenatal and post-natal issues on preterm birth. Hence we will use open questions for our pilot survey in January”. Prof Sandy Oliver, from the Institute of Education, re-introduced Seilin’s intention to explore this PSP as part of her PhD, which was welcomed by members of the Steering Group.



Seilin Uhm

To keep up to date with progress, visit the PSP’s website <http://eppi.ioe.ac.uk/pretermbirth>. For more information, please contact Seilin Uhm (s.uhm@ioe.ac.uk, 020 7612 6532) or follow the Twitter feed @PretermBirth.

Eczema



Tessa Clarke

The Centre of Evidence Based Dermatology at the University of Nottingham, in collaboration with the JLA, had a phenomenal response to the first Eczema PSP survey, bringing in a total of 1100 research uncertainties. The team has now processed the data from the first survey and the list of research uncertainties is ready to be ranked in the second survey, with the final prioritisation workshop planned for January 2012. You can find more information about the partnership through the ‘HOME’ website at www.homeforeczema.org. For more information, contact Tessa Clarke, Senior Clinical Trials Development Manager at Tessa.Clarke@nottingham.ac.uk

Cleft Lip and Palate

Edit Walsh from the Cleft Lip & Palate Association (CLAPA) reports: “Since the Cleft Lip & Palate PSP launched its survey at CLAPA’s annual conference in Manchester in September, we have collected 352 unanswered questions from 160 of our stakeholders. The largest group of respondents (45 per cent) is carers or relatives of someone with cleft, while 23 per cent are adults with cleft. Over a quarter of replies (27 per cent) have come from health professionals, with cleft surgeons and specialist



Edit Walsh



cleft nurses leading the way! The rate of reply from young people with cleft is relatively low so the steering group is planning to set up a focus group on 17 December for children and young people to talk about this topic and have their views represented. At the moment we are still collecting further uncertainties: the paper copy of the survey has just gone out to CLAPA members and we hope this will bring in many more responses. The survey deadline is 30th November, after which the next step will be to check all submitted questions and weed out all duplicates and questions that have already been answered and get a list of true uncertainties.”

If you have an unanswered question about clefting, please participate at www.clapa.com/survey. Alternatively you can email info@clapa.com for a copy of the survey, or call 020 7833 4883 to respond over the phone. For more information please contact Katherine Cowan: katherine@katherinecowan.net.



Tinnitus

This new PSP is being supported by the British Tinnitus Association (BTA), in partnership with the NIHR National Biomedical Research Unit in Hearing and the Judi Meadows Memorial Fund. David Stockdale, Chief Executive of BTA, said “The Tinnitus Priority Setting Partnership is a very exciting project to be involved with. It has been set up to identify the many questions about tinnitus assessment, diagnosis and treatment that remain unanswered. We hope that the outcome of the PSP will then enable more targeted research into tinnitus. It’s a fantastic opportunity for everyone involved in the condition and the British Tinnitus Association is delighted be supporting it.” To find out more, visit the Tinnitus PSP micro-site at: www.tinnitus.org.uk/JLA.



Good news for the Asthma Priority Setting Partnership

By Mike Thomas PhD FRCP, Asthma UK Senior Research Fellow, University of Aberdeen and Anne Bruton PhD MA (Cantab) MCSP, Reader in Respiratory Rehabilitation, University of Southampton

The BREATHE (Breathing Retraining for Asthma Trial of Home Exercises) study has been approved for funding by the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) board. This area was identified by the JLA Asthma Priority Setting Partnership as a priority research area for people with asthma, and this was a major factor in succeeding in securing funding in a tight financial environment. The project is a collaboration between the Universities of Aberdeen and Southampton, with Dr Mike Thomas as the Chief Investigator and Dr Anne Bruton as the Southampton lead investigator. It builds on previous work done at these two centres on the effectiveness of physiotherapist-taught breathing exercises to treat asthma.



Mike Thomas

There is now a strong body of evidence (awarded 'A-grade' status in a recent British Thoracic Society assessment of physiotherapy techniques for adult respiratory patients) to show that a short course of





Anne Bruton

physiotherapist-taught breathing exercises - consisting at the core of instruction in slow, steady nasal diaphragmatic breathing and discouraging hyperventilation - can improve health status for adult asthmatics who remain troubled by their asthma despite standard pharmacological therapy. As this describes the majority of asthmatics in the UK today, these techniques potentially have wide relevance to patients as an adjuvant to standard management. However, access to suitably trained respiratory physiotherapists is very limited, and most who could benefit don't currently have access to such treatments.

The multi-disciplinary trial group (including pulmonologists, primary care physicians, physiologists, physiotherapists, health psychologists and health economists) hopes to adapt the core elements of the programme, previously shown to be effective in 'face-to-face' physiotherapy, as an interactive DVD or internet download, to allow patients to learn and practise these simple techniques in their own home. The study will run through the Southampton Primary Care Research Network, and recruit broadly for primary care asthma patients.

For more information please contact drmike.thomas@btinternet.com or ab7@soton.ac.uk.

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The Top 10 Life after Stroke research priorities have been agreed!

By Dr Alex Pollock, Research Fellow at the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Unit, Glasgow Caledonian University



Alex Pollock

The Life after Stroke in Scotland PSP held its final consensus meeting on 16 November.. This was the final stage of 18 months of work to enable equal participation in all stages of this priority setting process.

Twenty eight participants (16 stroke survivors/carers and 12 health professionals) met at Glasgow Caledonian University and filled the meeting room to capacity. People travelled from as far as Aberdeen in the North East and Oban in the West – making the first cup of coffee particularly welcome! A community minibus brought stroke survivors from across the central belt of Scotland. The participants had been invited to ensure a group which was representative both in terms of where they came from in Scotland and (for the health professionals) their profession. A wide range of health professionals are involved in stroke care, and those in attendance covered nursing, medicine, physiotherapy, occupational therapy, speech and language therapy, neuropsychology, orthotics, orthoptics and social work. There were challenges in the organisation of such a representative group – in particular, difficulties for health professionals negotiating time away from work and the limited budget for meeting expenses which prevented the PSP offering overnight accommodation to all but those living furthest away.

Lester Firkins, who had travelled up to Glasgow to chair the meeting and was accompanied by Mark Fenton from the UK Database of Uncertainties about the Effects of Treatments (UK DUETs), started the day with a short introduction to the background of this PSP and the work done to date.





Participants then split into three groups (with stroke survivors/carers and health professionals divided equally between the groups), and moved to separate rooms to begin the process of prioritisation. Each group was facilitated by an independent person who had not been involved in the PSP.

There were 24 treatment uncertainties which each group had to rank. Each of the treatment uncertainties was written on an A4 card which had, on the back, details of (i) what the original submitted uncertainty was, (ii) who had submitted the uncertainty (stroke survivor, carer, health professional, from guidelines/published research recommendations) and (iii) the numbers of people voting for the uncertainty during the interim prioritisation process and

the ranking assigned from this voting. The three groups tackled the task of prioritising the uncertainties in their own ways. One group spread the cards across a table, with participants standing around it, and physically sorted the cards, while the other two groups went through each of the cards individually and decided whether it was 'high', 'middle' or 'low' priority. Once this task was done the piles of high, middle and low were then re-appraised and ranked accordingly.

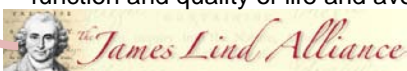


Patients', carers' and clinicians' top 10 priorities for stroke research

1. What are the best ways to improve cognition after stroke?
2. What are the best ways of helping people come to terms with the long term consequences of stroke?
3. What are the best ways to help people recover from aphasia?
4. What are the best treatments for arm recovery and function, including visual feedback, virtual reality, bilateral training, repetitive task training, imagery/mental practice, splinting, electromechanical and robot-assisted arm training and botulinum toxin.
5. What are the best ways to treat visual problems after stroke?
6. What are the best ways to manage and/or prevent fatigue?
7. What are the best treatments to improve balance, gait and mobility, including physiotherapy, gait rehabilitation, visual and auditory feedback, electrical stimulation, different types of ankle foot orthoses and electromechanical assisted gait training?
8. How can stroke survivors and families be helped to cope with speech problems?
9. What are the best ways to improve confidence after stroke, including stroke clubs/groups, offering support, one-to-one input and re-skilling?
10. Are exercise and fitness programmes beneficial at improving function and quality of life and avoiding subsequent stroke?

While the participants enjoyed some lunch and chat, Lester and Mark entered the ranking from each of the three groups onto a spreadsheet. The result of this was very encouraging, as there was a high level of agreement between the groups. After lunch, everyone gathered in one large horseshoe shaped group, with a line of tables running down the middle. The combined results were presented to the group, and a lively discussion ensued. After a break, the group quickly reached consensus on the final top 10.

Much of the debate was around questions which were 'similar' and whether both versions should feature in the top 10. For example, there was one question about the effect of interventions for cognition and another for memory, and both were viewed as highly important. However, memory is one component of cognition, so in this



case the group decided to have the question about cognition in the top 10, but not the question about memory, as they agreed this was encompassed within cognition. Two questions about communication impairment were debated – one about interventions for aphasia and another about ways to help stroke survivors and families cope with communication problems: in this case it was agreed that these were clearly different issues, and both remained in the top 10.

Interestingly, two of the questions which made it into the final top 10 were related to the impact of stroke rather than to specific stroke impairments. These questions covered coming to terms with life after stroke and the issue of confidence after stroke. These questions were clearly highly important to stroke survivors, and the case for including them was argued very eloquently and convincingly, with stroke survivors highlighting to the health professionals that addressing specific impairments was not important unless the stroke survivor had the confidence and support to get out of the house and participate in activities.

At the end of the day there was a discussion on the dissemination of the top 10. Early that morning, one of the group's participants had been interviewed live on Radio Scotland (800,000 listeners) – an interview highlighting the importance of stroke survivors working on an equal basis with health professionals to set the research agenda. An article has been commissioned by Society Guardian and a poster accepted for presentation at the UK Stroke Forum. A number of further strategies were agreed for dissemination and reporting, and the lead researchers are now working hard on this next stage of the project.

For further information, please contact: Alex.Pollock@gcu.ac.uk. Or go to www.askdoris.org/D_JLA.asp.



A personal view: living with Lyme disease

Stephanie Woodcock, a former laboratory microbiologist, describes her experience of Lyme disease.

I became ill in the mid 1980s and the illness defied diagnosis. I found myself enduring a plethora of awful symptoms such as malaise, extreme weakness, tender glands, joint pains, dizziness, memory loss and many other sudden deficits of mental function. These were very frightening times and I realised I was going to have to research my illness myself. I did remember that tiny insects had bitten me a few weeks beforehand.



Stephanie Woodcock

The illness waxed and waned and only on rare good days could I manage to read my microbiology textbooks and other journals. There was no internet in those days. I was suspicious about the bites and turned to chapters on arthropod-borne disease. I found information about Lyme disease and I recognised the symptoms. I learned that, only three years beforehand, Burgdorfer had discovered Lyme disease was caused by a spirochaete, *Borrelia burgdorferi*. Given the range and strange nature of my symptoms, this fact seemed a vital clue. From first principles of microbiology I knew that a test for this would be very specific. None of the general tests would pinpoint a disease such as that. In 1986 my first Lyme test proved negative. I accepted the result at face value. However, I realised that this was not necessarily the end of the road. Again, it was possible to reason from first principles that if any unknown spirochaete



were to be involved in my ill health, then the test I'd received might not include the right antigens to identify it. If that were so, it would still be possible to have an unknown spirochaetal disease that might be similar to classic Lyme.

I decided to push on and get myself treated with antibiotics on a 'just in case' basis. My own GP said that he found my reasoning "perfectly logical." That was good because I had to persuade him to treat me! Initially my response was slow, almost imperceptible. On two occasions I was removed from treatment but relapsed almost straight away. I had to beg to be treated again. After about a year my improvement was palpable. After three years of simple antibiotic treatment I was able to say to my GP, "I think I'll stop now." From then on I've never looked back and I've never relapsed.

I feel so sorry for others in a similar situation. I hope that by participating in the JLA PSP I can highlight the difficulties and uncertainties that my case gave rise to both for my GP and myself. I'll always be grateful to my GP who took a chance for me, saw that in the long term I responded to treatment, and got me better.

For more information on Lyme disease, go to www.lymediseaseaction.org.uk

EVENTS

Cochrane Colloquium

This year the Cochrane Colloquium took place in Madrid in October, and the JLA received a warm and enthusiastic welcome. Sally Crowe attended and enjoyed several opportunities to talk about the work of the JLA. The JLA is keen to seek opportunities for close working with Cochrane Review Groups on all matters of priority setting – not least the PSPs' prioritised areas of research which need to be addressed in new or updated reviews. It was also an excellent opportunity for the JLA to hear about other work in priority setting, research outcomes prioritisation, and consumer engagement in systematic reviews, all of which we can reflect on and use in the further development of the JLA Guidebook. The Cochrane Agenda and Priority Setting Methods Group became a registered entity within The Cochrane Collaboration the week after the colloquium. The Methods Group is developing a website, and working with the JLA to build a mailing list to facilitate discussions on agenda and priority setting methods for research, focussing on clinician and patient perspectives.



Evidence 2011

Evidence 2011 took place in West London in October and showcased the ideas, processes and best practices that form the foundations of an evidence-based approach to developing and implementing cost-effective healthcare strategies. In a lively and well-attended session chaired by Iain Chalmers, Sally Crowe made the case for involving the public in healthcare research debates. Gill Gyte described how to use consumer information to inform clinical guidelines, and Kristina Staley gave examples from her review of the ways that patient involvement can make a difference to clinical research.



Kristina Staley, Gill Gyte, Sally Crowe and Iain Chalmers



Cochrane Italian Network



Laura Amato, Vanna Pistotti, Katherine Cowan and Alessandro Liberati

In November, Katherine Cowan was invited to attend the Italian Cochrane Network's 16th annual meeting at the Istituto Superiore di Sanità in Rome, which focused on the theme of how to make clinical research better. Participating in a series of presentations on strategies for delivering and promoting patient-oriented research, Katherine described how the JLA involves patients in research priority setting, including the rationale for doing so, the challenges of involvement, and the practical lessons the JLA has learned from its PSPs. For more information on the Italian Cochrane Network, go to www.cochrane.it.

IN PRINT

Buckley, B., Grant, A. and Glazener, C. (2011) 'Case study: A patient-clinician collaboration that identified and prioritized evidence gaps and stimulated research development', *Journal of Clinical Epidemiology*, doi:10.1016/j.jclinepi.2011.03.016.



Abstract

Objective: To assess the effect of a JLA research prioritisation partnership that aimed to influence the research agenda relating to urinary incontinence (UI).

Study Design and Setting: Research often neglects important gaps in existing evidence so that decisions must be made about treatments without reliable evidence of their effectiveness. In 2007-2009, a JLA partnership of eight patient and 13 clinician organizations identified and prioritised gaps in the evidence that affect everyday decisions about treatment of UI. The top 10 prioritised research questions were published and reported to research funders in 2009. A year later, new research or funding applications relating to the prioritised topics were identified through reviews of research databases and consultation with funding organizations, elements of the research community, and organisations that participated in the partnership.

Results: Since dissemination of the prioritised topics, five studies are known to have been funded, three in development; five new systematic reviews are under way, one is being updated; five questions are under consideration by a national research commissioning body.

Conclusion: The partnership successfully developed and used a methodology for identification and prioritisation of research needs through patient-clinician consensus. Prioritisation through consensus can be effective in informing the development of clinically useful research.

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.



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

You can also follow us on Twitter: www.twitter.com/LindAlliance.



CURRENT AFFILIATES

The JLA currently has 418 Affiliates, most of whom are listed on our website. The Affiliates programme is for organisations and individuals who identify strongly with the objectives of the JLA, and 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 to sign up.

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. 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 January 2012.

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