MESSAGE FROM THE CHAIR

Dear colleague,

Marks & Spencer, John Lewis and Argos are all convincing us that it's Christmas already, so can I also add our seasonal best wishes to you all – but with no sales agenda attached!

Everything we do, and learn from, is rooted in our Priority Setting Partnerships (PSP). So it is a great excitement to us that we have just completed our fourth one – prostate cancer. A huge amount of work has gone into getting the PSP to this stage, and it was fantastic to get everyone together for the workshop and to come away with a top ten list agreed by patients and clinicians alike. In particular, thank you to the steering group, Vincent Gnanapragasam, Emma Halls, Kate Holmes, Li Lophatananon, Ken Muir and Sandy Tyndale-Biscoe for their commitment, enthusiasm and hard work throughout the process – a great team to work with. We now have six further PSPs in progress, and six more in the early stages of development. PSPs for schizophrenia and type 1 diabetes are scheduled to complete early in 2011.

In other news, Mark Fenton, Editor of the UK Database of Uncertainties about the Effects of Treatments (UK DUETs), and I are presenting to NICE Guidance producers in London and Manchester later this month. We are planning to share the work we both do, with a view to helping them understand how, potentially, a process of prioritisation could be applied to their research recommendations.

Thanks, as always, for your support

Lester Firkins, Chair, James Lind Alliance
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 PSP should visit www.JLAguidebook.org or contact Patricia Atkinson (patkinson@lindalliance.org).

Prostate cancer
The Prostate Cancer PSP completed its final priority setting exercise in a workshop in London on 4th October – the culmination of almost exactly two years work led by the Prostate Cancer Support Federation and Prostate Action (formerly the Prostate Cancer Research Foundation, now merged with Prostate UK, funding research and education to beat prostate disease). A meeting comprised equally of patients and clinicians worked hard, in two small groups, facilitated by the JLA, to discuss, debate and refine the shortlist of prostate cancer treatment uncertainties. Finally, there was almost unanimous agreement of the top 10 priorities for research – in fact, the shortlists agreed separately by both of the small groups were identical in their first to seventh priorities, making aggregation of the data very straightforward.

“It is hard to believe that after nearly two years we have finally got the prostate top 10,” said Emma Halls, Chief Executive of Prostate Action. “Our aim now is to ensure this list is published as widely as possible so we can start to influence the research agenda.”

Sandy Tyndale-Biscoe, Chairman of the Prostate Cancer Support Federation added: “What a fantastic outcome! On behalf of all people affected by this disease, a huge thank you to all of you for putting so much effort into this so successful exercise. The unanimity of the result, coming as it does from such a broad mix of patient and clinician types, gives it tremendous authority. We, the prostate cancer community, now need to embark on a mission of promoting the results to the research funding community, asking very difficult questions of those who are funding research into areas that are not up there in the top ten.”

The top 10 prostate cancer research priorities are currently being prepared for publication by the steering group and will be published in the next edition of the Newsletter. Work is also due to start to bring research funders’ attention to the priorities, starting with the National Institute for Health Research Health Technology Assessment programme. We look forward to keeping you informed of future developments.

Type 1 diabetes
The Type 1 Diabetes PSP is progressing well. Five hundred and eighty three people completed the online and paper survey asking for their treatment uncertainties, including people with type 1 diabetes, family members and healthcare professionals. In total, they submitted 1141 treatment uncertainties. Of these, 251 were not related to treatment of type 1 diabetes and were excluded from the current process, but are interesting and will receive attention later on in the project. The steering group agreed categories for the submitted treatment uncertainties before the survey, so all submissions have been allocated to these. They include condition management (medication, monitoring, and lifestyle, for example), pregnancy, and delivery of care. There were many duplicates...
Schizophrenia
“Since I have been in post, the Schizophrenia PSP’s interim prioritisation exercise has got underway and we’ll be holding a workshop to agree a shared list of research priorities for patients and clinicians in London in January,” says Jo White, Research Assistant at Swansea University’s School of Medicine, who is co-ordinating the PSP. “The long list of 237 unanswered research questions about the treatment of schizophrenia has gone out to our partner organisations and individuals representing patients and clinicians. They have been asked to choose the 10 which they most want to see prioritised for research, and rank them. While some partners are doing this individually, others are consulting with their members, colleagues or peers to identify their shortlist. I would like to thank and encourage our partners to continue with their good work.”

For further details of the PSP please contact Jo White (j.white@swansea.ac.uk) or Katherine Cowan (Katherine@katherinecowan.net).

Life after stroke in Scotland
The process of gathering uncertainties for the Life after Stroke in Scotland PSP is now underway, with the steering group taking a ‘roadshow’ around Scotland. The group had an information stand and collected uncertainties from people attending a variety of events, including:

- Scottish Stroke Nurses Forum (SSNF) annual conference
- Scottish Stroke Research Network (SSRN) annual conference
- NHS Greater Glasgow & Clyde Stroke AHP study day
- Lanarkshire ‘stroke walk’
- World Stroke Day event for patients and carers (hosted by SSRN)
- Scottish Stroke Care Audit committee meeting

The group will also have an ‘ideas fair’ stand at the UK Stroke Forum conference, 30th November – 2nd December 2010. The steering group plans to use the stand to collect uncertainties from as many conference delegates as possible. As well as targeting these events, the steering group has either completed, or confirmed dates for attendance at groups within most of the 11 mainland NHS Health Board areas, and has also recruited volunteers to present the project to patient groups on some of the Scottish islands. “The information leaflet and response form which have been developed for this project are available from www.askDORIS.org - click on the red ‘Life after stroke in Scotland research priorities project’ button”, says Alex Pollock, one of the project leads based at the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Unit Glasgow Caledonian University.

Sally Crowe on sally@crowe-associates.co.uk.

Does continuous blood glucose monitoring reduce the frequency of long term complications of diabetes?

Jo White

Alex Pollock
An audio presentation will also soon be available on the website.

For more information: contact Alex Pollock: Alex.Pollock@gcu.ac.uk

**Ear, nose and throat (ENT) – aspects of balance**

Steve Sharp, Knowledge Manager at NHS Evidence - ENT and audiology, reports:

“The ENT partnership’s *Aspects of Balance* project continues to progress. Following analysis of the online and postal survey conducted over the summer months, 669 raw uncertainties were identified from 258 patient and clinician responses. A wide range of both drug and non-drug treatment questions were submitted, and these raw uncertainties are currently being de-duplicated to create indicative uncertainties, and checked to ensure that they remain true uncertainties. These will progress to the final prioritisation stage. It has been a major challenge to reflect patient priorities faithfully while complying with the UK DUETs inclusion criteria, and we have addressed this issue by creating an additional list of non-treatment uncertainties that may be suitable for alternative research funding. The next step in the process will be to finalise and circulate the verified treatment uncertainties to the wider membership for ranking by priority. This will generate the final top 10 list of uncertainties to be presented for research funding.” Further information on this PSP can be obtained from Jo White at jo@entuk.org.

For an insight into the patient experience of balance disorders, see our interview on page 5.

**Pressure ulcers**

The Pressure Ulcer Partnership is holding an introductory meeting for people who have experience of pressure ulcers (either providing care and treatment, or receiving it), and representatives of groups and charities that have an interest in management and treatment of pressure ulcers. The purpose of the meeting is to discuss treatment and prevention uncertainties in the care and management of pressure ulcers and how research into pressure ulcers can be improved. It will also be an opportunity to understand how a JLA PSP works and a chance for participants to consider how to get involved. The meeting will be on Tuesday 30th November in York. To find out more, visit [www.jlapressureulcerpartnership.co.uk](http://www.jlapressureulcerpartnership.co.uk).
INTERVIEW: Labyrinthitis – living with dizziness

We’ve all felt dizzy at some point in our lives, whether from spinning on the spot as children or simply from being car sick or sea sick. It’s an unpleasant feeling. But can you imagine it lasting not just for a few moments, but for days, months or even years at a time? Labyrinthitis is an inner ear infection which causes dizziness for extended periods of time. Emma, co-founder of patient website Labyrinthitis.org.uk, talks to Katherine Cowan, Editor of this newsletter, about what it’s like living with dizziness.

Until I looked at your website, Emma, I hadn’t heard of labyrinthitis. Can you tell me a bit about it?
It’s basically an inflammation of the inner ear, which causes a feeling of dizziness. It’s generally caused by a virus, often a normal cold virus, which travels via your blood to your inner ear. Normally it lasts about six weeks, but in some cases the virus causes damage which can cause further problems and takes longer to recover from. For some, the damage will never heal. In my case, the virus had caused asymmetry to my inner ear and left me feeling dizzy for eight years. And that’s what sets it apart from other inner ear conditions – the dizziness isn’t episodic, it goes on for a long time.

Who is most likely to be affected?
I get emails every day from a huge range of people, from age 12 to 80, men and women. I’ve noticed quite a lot of people who work with children have got in touch – so maybe people who are particularly exposed to germs are more likely to get it. Basically, it seems to affect anyone.

Is very much known about it?
I think it’s becoming more known, thankfully. When I got it eight years ago I went to several GPs, and they were completely clueless, or just fobbed me off with medication. In the last few years, it seems that awareness is growing. But compared with other conditions, there seems to be a lack of training on how to treat it.

So what does it feel like to have labyrinthitis?
Well, it’s to do with false sense of motion. It can feel like you’re walking on a trampoline. You can get a spinning feeling inside your head – like a snow dome, with little bits in your head always moving. You can also get visual disturbances, it can seem like things which are still are moving slightly, or flickering. There’s also a sense of imbalance – unsteadiness on the feet.

When you first became dizzy, how did the people around you react?
The hardest thing about it is that you look fine, you sound fine, so people can’t see that you’re ill. I tried really hard to keep living a normal life, and because I wasn’t bed-ridden, people thought I was OK, but daily activities were really quite hard for me. It felt very isolating.

Is that why you set up the website, www.labyrinthitis.org.uk?
When I got labyrinthitis there was so little information or support out there. When I met Ilia [the site’s co-founder] it helped me so much as she knew exactly how I felt. I wanted to make sure other people had that support and didn’t feel alone.
Besides the physical symptoms, how else does labyrinthitis impact on you?

It can make things hard socially. Things like going to a restaurant or the cinema were very hard, as was being out at night or in a busy environment, like going shopping. Although I tried to make myself do it, I definitely didn’t go out as much. I’d always have to think ahead. If someone invited me away for a weekend I’d be worrying about how I would feel as it could be so unpredictable at times. It put life on hold for me.

What about the practical everyday things, like getting out of bed, getting dressed and cooking?

I wasn’t too bad, although it would have been harder if I’d had to hold down a job or had kids – I was at university at the time. If I did things like cleaning or gardening I’d be spinning. It felt uncomfortable, but I could move around. I’ve had emails from people though who literally can’t get out of bed.

So what tips do you offer people who are suffering from this?

Where possible, it’s really important to try and keep going and to stay active. I’d also suggest they try and get a referral as soon as possible for Vestibular Rehabilitation Therapy – VRT. You can get that via an Ear Nose and Throat (ENT) specialist, or your GP can refer you. The quicker you can do that the better, and in my view the less medication you take the better as it just masks the problem.

Thinking about the work of the JLA Aspects of Balance PSP, what are the major uncertainties in labyrinthitis for you?

I think there are a lot, but my main one is around the limited knowledge among medical professionals about the condition and VRT. There needs to be more research into VRT and how it works, and into the effectiveness of individualized exercises over generic ones, so more money can be put into it and more facilities provided.

Finally, Emma, with regards to you personally, are you cured?

I’m not cured, but I’m a lot better than I was. The VRT did that, although it was only really after one year of doing VRT exercises that I saw improvements. You have to really persevere with it. I can do everything in life now. While the dizziness doesn’t go away completely, when it gets to a more manageable level, you learn to live with it and you stop noticing it so much.

To find out more (including details of the Balance Conference on 25th June 2011) go to www.labyrinthitis.org.uk or email iliaandemma@hotmail.com.

RECENT EVENTS

INVOLVE conference 2010

All four members of the JLA team were delighted to attend this year’s INVOLVE conference in Nottingham. Attended by people with a common interest in public involvement in NHS, public health and social care research, this is a key event for information and knowledge sharing. Participants included members of the public, service users, researchers, research commissioners and representatives of voluntary sector.
organisations. Sally Crowe was invited to chair two sessions. Lester Firkins hosted the popular Soapbox, which enabled those with a passion about an aspect of public involvement in research three minutes in which to have their say. It was great to see how awareness of the JLA and its work has grown. We would like to welcome the 30 new affiliates who signed up while attending the conference, and look forward to sharing news and good practice with you.

Left to right: Katherine Cowan, Patricia Atkinson, Sally Crowe and Lester Firkins

Scottish School of Primary Care conference
Earlier in the year, the JLA’s Chair, Lester Firkins, was invited by Professor Frank Sullivan to give a presentation at the annual Scottish School of Primary Care (SSPC) conference. Writing recently in the SSPC’s E-Newsletter, in a follow-up to the event, Lester took the opportunity to describe the JLA process, and to share his journey to involvement. To read the article, go to www.sspc.ac.uk/enewsletter/lester.htm.

If you would like the JLA to participate in your event, let us know. We can then promote it in the Newsletter.
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, please visit our online Guidebook: www.JLAguidebook.org. The Guidebook features examples of existing PSPs, including documents and templates to download and use.

CURRENT AFFILIATES

The JLA Affiliates programme is for organisations and individuals who identify strongly with the objectives of the JLA, and who 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.

The JLA currently has 269 Affiliates, most of whom are listed on our website.

The UK Cochrane Centre (UKCC) has been a JLA Affiliate since 2005. The UKCC was established at the end of 1992, by the National Health Service Research and Development Programme and is now part of the National Institute for Health Research. It is one of the Centres in the international Cochrane Collaboration, the world’s largest organisation dedicated to preparing, maintaining and promoting access to systematic reviews of the effects of healthcare interventions, with more than 4400 full Cochrane reviews produced to date. The UKCC provides training and support to members of the Collaboration and acts as a knowledge broker between its work and decision makers, in the UK, Ireland and some other countries. Professor Mike Clarke, Director of the UKCC (who took over from the first Director, Sir Iain Chalmers, in 2002) told us, “We are delighted to be an Affiliate of the James
Lind Alliance. Around half of all Cochrane reviews identify uncertainties about the effects of interventions, and the partnerships of patients and practitioners established within the JLA provide an excellent opportunity to turn those uncertainties into research, in order to produce the evidence we all need to take well informed choices about health care."

For more information, go to [www.cochrane.org](http://www.cochrane.org).

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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 and clinician involvement in research priority setting, please visit [www.lindalliance.org](http://www.lindalliance.org). In the Publications section you will find a downloadable bibliography, along with an archive of useful JLA publications.

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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 January 2011.

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*Happy New Year and all the best for 2011!*