



Affiliates Newsletter – March 2011

MESSAGE FROM THE CHAIR

Dear colleague,

In this newsletter we thought you may appreciate an update on 'What Happened Next?' to the JLA Priority Setting Partnerships (PSPs) that have been completed. While the ultimate outcome for this work is if there is a real change in what research into treatment uncertainties is funded, it is also interesting to see if partners stay in touch and continue to develop joint working.

The JLA always encourages PSPs to undertake the dissemination process themselves, as the uncertainties they identify are theirs and not ours. Indeed, as we guide more and more PSPs, limitations in our capacity mean that partners need to own and take forward this element. This sits well with our philosophy that the partners – patients, carers and clinicians – are the owners of the work, while we at the JLA are simply facilitators.

Following the completion of our Schizophrenia PSP in January, we are also including an extended interview with someone who lives with schizophrenia, making sure we remain grounded in remembering exactly why all this effort is so important.

Thanks, as always, for your support,

Lester Firkins, Chair, James Lind Alliance



NEWS

JLA Guidebook – latest version now online

The JLA Guidebook is the definitive resource on establishing JLA Priority Setting Partnerships. Evidence-based, it provides practical guidance on how to take patients, carers and clinicians through the process of identifying treatment uncertainties and prioritising them for research: from setting up a PSP and recruiting participants, to running a final priority setting workshop and taking the top 10 priorities to funders and researchers. Since its launch in May 2010, the Guidebook has attracted over 23,000 visitors. The JLA process is always evolving, however, so to ensure that the Guidebook incorporates the latest methodological developments and good practice examples, it has recently been updated. The updates include materials from the Schizophrenia PSP, the Type 1 Diabetes PSP, the ENT Aspects of Balance PSP and the Stroke in Scotland PSP. This latest version, version three, can be found at www.JLAguidebook.org, and can be downloaded as a PDF document free of charge. As always, we welcome your feedback and suggestions, which can be submitted via the website in the Contact Us section.



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).

Type 1 Diabetes

The Steering Group will be agreeing the shortlist of type 1 diabetes treatment uncertainties soon and partners will be asked to vote on these to identify those they think are most important. The final priority setting workshop has been set for May 2011, in London. For further information please contact Sally Crowe on sally@crowe-associates.co.uk or ring 01844 216929.

Life After Stroke in Scotland

The Life after Stroke in Scotland priority setting project is progressing well. The closing date for the submission of treatment uncertainties has now passed. The group has collected over 500 treatment uncertainties, with around a third of these coming from either individual patients or patient groups. The Steering Group is now starting the daunting task of checking the uncertainties submitted, and planning the methods of interim prioritisation.



For further details, or to get involved, please contact Dr Alex Pollock, Research Fellow at the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Unit, Glasgow Caledonian University (Alex.Pollock@gcu.ac.uk). Or go to www.askdoris.org/D_JLA.asp.

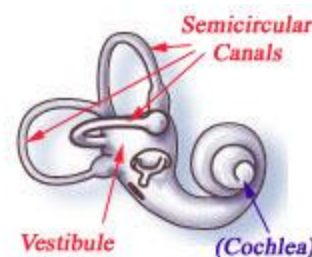


Head and Neck Cancer

The aim of the Head and Neck Cancer PSP is to identify from patient and clinician perspectives the unanswered questions about head and neck cancer treatment, and then to prioritise those which patients and clinicians agree are the most important. An initial awareness meeting was held on 3rd March, supported by ENT UK and the Head & Neck 5000 project. Clinicians, patients and carers were well represented and the PSP is now moving to the stage of gathering their treatment uncertainties. For more information, please contact Jo White at Jo@entuk.org, or visit the JLA website: www.lindalliance.org/HeadandNeckCancerJLAPrioritySettingPartnership.asp.

Ear, Nose and Throat – Aspects of Balance

The Aspects of Balance PSP is now progressing through the interim priority setting stage, prior to a final workshop later in the year. A long-list of 147 questions to vote on has been compiled from the raw uncertainties submitted in the initial survey, and grouped under major treatment categories. This has been circulated to patient and professional respondents to elicit their top five uncertainties. Unsurprisingly, the majority of questions revolved around diet, lifestyle and self-help interventions, in addition to the most common drug treatment and vestibular rehabilitation interventions.



"The main challenge for the Steering Group throughout the process so far has been to ensure representative input from both patient and professional communities, and this will be imperative for the final workshop", said Steve Sharp, Knowledge Manager at NHS Evidence - ENT and audiology, who has been managing the collection and checking the uncertainties. Reflecting on the process itself, he added, "Another challenge lay in translating the submitted raw uncertainties into questions to vote on; the expert opinion of clinicians was invaluable in this process. The efficiency of future PSPs would be improved by the availability of standardised processes and templates for the initial survey design and analysis, in addition to the availability of advice from previous steering groups. A past and present PSP discussion group or wiki may be worth establishing for this purpose, with consenting contacts from previous PSPs joining such a group to offer advice when required. A further efficiency saving development will be the forthcoming mass import function for UK DUETs, which will allow large numbers of verified uncertainties to be imported in bulk from sources such as the Cochrane Library to create UK DUETs records."



The final priority setting workshop is scheduled for 31st May. If you would like any further information on this PSP, please contact Jo White jo@entuk.org.

Pressure Ulcers

The initial awareness meeting for the Pressure Ulcer PSP was on 22nd March in York. Practitioners involved in pressure ulcer treatment and care, and people who have experience of living with, or being at risk of pressure ulcers, met to discuss treatment and prevention uncertainties associated with pressure ulcers. There were also presentations and discussion about gathering uncertainties from different groups, especially elderly and vulnerable people. Many of the participants offered



tangible help, and a Steering Group will be formed once a Research Fellow has been appointed to support the work. For further information on the next stages please contact Dr. Mary Madden (mary.madden@york.ac.uk) or Sally Crowe (sally@crowe-associates.co.uk). The Research Fellow post is being advertised at www22.i-grasp.com/fe/tpl_YorkUni01.asp?newms=jj&id=42005.

Lyme Disease

The JLA Lyme Disease PSP is now underway. Lyme disease is an infectious disease transmitted to humans by the bite of an infected tick. It is endemic throughout the UK and the number of laboratory-confirmed cases is rising steadily. As a multi-system disease that has been relatively rare or unrecognised, expertise in treating it is spread thinly across a large number of specialties. This PSP is important because it is the first serious examination of Lyme disease in the UK and the partnership will confer widely among clinicians and patients. Patient groups have been invited and invitations are currently being sent out to clinicians asking them to come to an awareness day on 18th May 2011 from 11:30am-3:00pm, at the Academy of Medical Sciences in London. At this session the JLA will introduce the PSP concept and explain why we need to know the uncertainties in diagnosis and treatment of Lyme disease. It is a free event and lunch is included. So if you are a healthcare practitioner with experience of treating the condition, please send contact details to conferenceteam@LymeDiseaseAction.org.uk. For further information on this PSP, please contact Stella Huyshe-Shires at Stella.Huyshe@LymeDiseaseAction.org.uk.



Pre-Term Birth

See our *Affiliates* feature on page 10 for news of this exciting new PSP.



SPECIAL FEATURE

Priority Setting Partnerships: what happened next?

Four years ago this month, the JLA Asthma PSP completed the JLA priority setting process. It came away from its final workshop with a top 10 list of treatment uncertainties, prioritised in collaboration between patients with asthma, their carers and the clinicians who treat them. This was the JLA's first completed PSP, and since then a further four have gone through the process and agreed their top 10, with at least three more due to do the same this year. So what difference has this made? What impact have the top 10 had on the health research agenda? Those who have completed the process report back to let us know what happened next.

Asthma PSP – completed March 2007

“Our work with the JLA highlighted a number of important research questions which people with asthma and healthcare professionals believe need to be answered,” said Leanne Metcalf, Assistant Director of Research at Asthma UK. “Some of these questions are now being explored by major funding agencies, including Asthma UK, and the results are likely to have a significant impact on the treatments and care that people with asthma receive. In addition, as the charity revises its research strategy, Asthma UK is seeking to directly relate these priority research questions to its funding decisions in the future.”



Leanne Metcalf





Mike Thomas

Elaborating further, Dr Mike Thomas, Asthma UK Senior Research Fellow at the University of Aberdeen, said “The prioritisation exercise showed that people with asthma feel that better evidence on the effects of breathing exercises for asthma is needed. There is promising early evidence that some forms of breathing exercises, such as those taught by physiotherapists or by Buteyko instructors, can help to improve asthma control and lead to improved quality of life for people with asthma.

However, studies to date have not provided sufficiently robust evidence to justify changing practice on a wide scale. At the moment such treatment is often difficult to for people with asthma to access, and they often have to go outside the NHS for it. Better evidence could lead to wider provision of such techniques within the NHS. Stimulated by the PSP, a research collaboration of experienced respiratory researchers from the Universities of Aberdeen and Southampton is hoping to obtain funding from the UK National Institute of Health Research (NIHR) to launch a large study that should provide definitive evidence in this area. The team includes experienced asthma doctors from GP and hospital backgrounds, nurses and physiotherapists, as well as health psychologists and health economic experts, who will assess the costs and benefits of providing breathing exercises more widely to people with asthma. A funding decision is expected soon.”



Stephen Holgate

Professor Stephen Holgate, Chair of the UK Respiratory Research Collaborative also commented: "Without this coming together of patients with the research community catalysed by the JLA, the subject of breathing exercises would never have been identified as one that received so much enthusiastic support".

Urinary Incontinence PSP – completed November 2008



Brian Buckley

“The Urinary Incontinence PSP seems to have prompted a considerable amount of research activity”, said Brian Buckley, Chair of The Bladder & Bowel Foundation and one of the PSP’s steering group members. “A year after completion and publication of its results, a consultation was conducted amongst PSP participants, elements of the research community, research funders and research databases to identify new research that relates to the questions identified by the PSP. Five related studies of varying size are known to have been funded and several more are in development, addressing six of the top 10 priorities, with two combined. All of this activity has been in response to some degree to the PSP’s work, which has been cited in

funding applications. A number of Cochrane systematic reviews have been initiated or are being updated. Some of these reviews are known to have been in direct response to the PSP work. Others are less direct responses but have been initiated in the context of the Cochrane review group that was integrally involved with the PSP, so it is likely to have had some influence, if indirect. Several of the questions identified by the PSP are under consideration by the UK’s major funding agency for research commissioning calls. This process is complex, and the PSP has been unable to maintain influence with regards to the progress of the topics. Some concerns have been expressed that the very specific questions identified and prioritised by the PSP through patient and clinician consensus might be altered by NIHR’s own topic prioritisation process. Finally, the PSP’s prioritised questions have also been recognised by two international academic groups that have an interest in incontinence research, so they will be considered by the international research community. For only one of the 10 prioritised questions has no specific related activity been identified.”



Vitiligo PSP – completed March 2010

Following the Vitiligo PSP, the top 10 uncertainties on the treatment of vitiligo have now been published in the British Journal of Dermatology. Dr Viktoria Eleftheriadou, Research Associate at the Centre of Evidence Based Dermatology, which led the PSP, reports:



Viktoria Eleftheriadou

“Our team has made efforts to ensure that the results of the Vitiligo PSP are widely disseminated to both clinical and research community. I have given oral presentations on the top 10 treatment uncertainties and the results of the Vitiligo PSP in September 2010 at the 16th Meeting of the European Society of Pigment Cell research in Cambridge and at the First Vitiligo World Congress in Milan. Maxine Whitton, Patron of the Vitiligo Society, also spoke about the project at the Patient Day meeting at the Vitiligo World Congress. Since March 2010, the vitiligo team has made various efforts to try to influence the research agenda based on the identified topics. Five research vignettes were submitted to the HTA

prioritisation panel and are now under consideration for funding. News on the results of the HTA prioritisation panel will be available around September 2011. Also, pharmaceutical company Clinuvel is currently preparing to run a pilot multi-centre trial on afamelanotide for the treatment of vitiligo, which was the sixth uncertainty in the top 10.

“At the Centre of Evidence Based Dermatology, two research ideas based on the top 10 are being developed into a trial protocol. Several factors, including feasibility, willingness of clinicians to recruit patients, convenience for patients and other methodological factors for clinical trials, had to be taken into account. Of course, it takes time to complete all the preliminary work needed to complete a trial protocol, but the topics the vitiligo team is currently working on are: the effectiveness and safety of hand held NB-UVB devices at home for the treatment of limited or early vitiligo; and the effectiveness of topical corticosteroids compared to topical calcineurin inhibitors.”

Prostate Cancer PSP – completed October 2010

“Following our final priority setting meeting in October 2010 we have been busy putting together articles for publication around our prioritised list”, said Emma Malcolm, Chief Executive of Prostate Action. “We have had interest from the Medical Research Council and National Institute for Health Research Health Technology Assessment programme, regarding the list, and look forward to it informing thinking about research into prostate cancer. It was a real privilege to be involved in something so important to the prostate community, and we very much hope that this work goes forward and informs decisions.”



Emma Malcolm



Sandy Tyndale-Biscoe

Sandy Tyndale-Biscoe, Chairman of the Prostate Cancer Support Federation, added, “Being involved with the Prostate Cancer PSP was both an honour and an eye-opener, and, in many ways, most rewarding. The challenge now is to get the funders to pay attention to the results and we need to work on this aspect.”



Schizophrenia PSP – completed January 2011

“Patients, clinicians and carers agreed a final ranked top ten questions in schizophrenia in London in January,” said Jo White, Research Fellow at the Mental Health Research Network Cymru, based at Swansea University, who is coordinating the next phase of the PSP. “The Steering Group has now established a dissemination strategy for the top ten, to bring it to the attention of research funders and to have maximum impact within the schizophrenia community. There are three dissemination routes: the scientific route, public understanding, and dissemination for action to policy makers and funders.”



Jo White

Keith Lloyd, Professor of Psychological Medicine at Swansea University and Consultant Psychiatrist who led the original exercise to identify the treatment uncertainties, described how the priority setting workshop impacted on his clinical practice: “Sexual dysfunction due to antipsychotic medication turned out to be a key topic prioritised by patients for further research. Clinicians typically give it less importance when making prescribing choices. The week after the JLA workshop, a patient came to see me in clinic wanting a change of antipsychotic medication. It turned out he wanted to change because of sexual dysfunction. Had I not taken part in the JLA process, I really don’t think the topic would have been on the agenda in the consultation”.



Keith Lloyd

Jo White added, “Our aim is to ensure this the list is published as widely as possible so we can start to influence the research agenda and to achieve maximum impact in the research community. Work is underway to bring research funders’ attention to the priorities, starting with the Health Technology Assessment programme. We look forward to keeping you informed of future developments.”

See below for a service user’s perspective of schizophrenia.

INTERVIEW: living with schizophrenia

The JLA Schizophrenia PSP recently completed its priority setting process, and is now working hard to secure publicity for and interest from funders in the top 10 treatment uncertainties. Schizophrenia is a mental illness that affects about one in a hundred people at some point in life. About a quarter recover within five years, but approximately two-thirds continue to experience fluctuating symptoms, while around 10 per cent experience severe long term incapacity¹. Tom (not his real name) is a London-based composer in his 50s. He was diagnosed with schizophrenia 20 years ago. He spoke to Katherine Cowan about living with schizophrenia.

Tom, can you tell me what led to your diagnosis of schizophrenia?

Well, I’d been ill for several years without knowing it. I was working full time and doing well, but I began to have constant paranoia and delusions. I thought there was a conspiracy against me. Like many people I went untreated, until it came to a crisis, and I was picked up by the police and sectioned under the Mental Health Act. I was sent to a hospital, an old institution, where I was diagnosed and treated. I was there for about 18 months. They say you’re more likely to be diagnosed

¹ www.rethink.org.uk

with schizophrenia in your early 20s, but I'd had no signs of it before my 30s. There was no particular trauma or event that I can relate the onset to. I was feeling very happy and doing well in life. It's really just a case of developing a chemical imbalance in the brain, and I suppose it goes to show that it can affect anyone at any time.

What was it like to be given a diagnosis of schizophrenia?

In a way I was relieved that people knew there was something wrong with me and that I was experiencing delusions rather than the horrible reality of a conspiracy. But I was also quite alarmed because I didn't know much about schizophrenia or mental illness, so I felt rather in the dark about what it meant.

What kind of treatment were you given?

Fortunately I responded well to medication, it seemed to alleviate the symptoms very well. I was offered talking therapy with a clinical psychologist, but it wasn't very successful – I know it's quite popular, but I personally didn't respond very well to it. I found it rather stressful.

Eighteen months is a long time to be in hospital. What impact did that have on your life?

It affected the way I functioned. I lost a lot of my social skills and became very institutionalised. When I was eventually discharged I found it difficult to do basic things, like make a cup of tea or prepare a meal. When you're in hospital all that is done for you – you don't have to think about things like shopping or housework. On discharge, my goal in life was to find paid work - I felt my life would be normalised if I got back into the world of work. I had a very talented social worker who helped a lot and encouraged me.

How did it affect your relationships with family and friends?

They were very supportive. Before I was diagnosed, I did lose touch with quite a number of friends because of feeling that they were conspiring against me, and I do regret that. But my main core of friends was very supportive. No one realised there was anything wrong with me until I went into hospital. When I was in hospital my mother did a lot of practical things, like looking after my flat, forwarding my post to me and seeing that my bills were paid.

So how do you manage your condition now?

My condition is stable really because of the medication I'm taking. I'm on a very low dose of medication which seems to maintain my mental health. I feel very fortunate that I respond well to it. My condition does impact on my ability to work – when I entered back into the workplace, it seemed to exacerbate it. After a few years, I relapsed and went back into hospital. So it was felt that work is not advisable for me. Socially I am sensitive that there is a lot of stigma attached to schizophrenia, so there are a number of friends to whom I've never mentioned my disability. I'm concerned that if they knew they might treat me in a different way or would reject me, or they'd become suspicious of me. Schizophrenia gets the worst press, and there is a risk that people might associate you with the negative publicity of people with schizophrenia committing acts of violence. With some people, one lives a lie really, keeping it from them.

Have you experienced discrimination because of your condition?

When I was trying to find work again, in interviews, the moment I said I'd been in a psychiatric hospital, all the barriers went up and I never heard from those people again. They didn't even have the courtesy to write and thank me for coming to interview. In spite of the legislation which applies to the workplace, I think there is still quite a lot of discrimination against people with schizophrenia.



Having said that, some allowances are made for my disability, so it's not all bad. I receive Disability Living Allowance so I'm exempt from paying council tax, and I get concessions on public transport, as well as to museums and sports facilities. Of course, if I was able to work, I wouldn't need these concessions.

Finally, what are your plans for the future?

I'm involved a lot in service user representation, which keeps me busy. I'm happy to represent the views and interests of service users who are perhaps less able than me. I'm also very happy to have time to compose music. I don't have major plans for the future. I really just hope life continues as well as it does in my state of recovery, and that life is stable, relapse-free and of a good quality.

For more information about challenging the stigma surrounding schizophrenia and mental health, please visit www.time-to-change.org.uk.

IN PRINT

Viergever, R., Olifson, S., Ghaffar, A. and Terry, R.
A checklist for health research priority setting: nine common themes of good practice. *Health Research Policy and Systems* 2010, 8:36



HEALTH RESEARCH POLICY
AND SYSTEMS

Article references the JLA Guidebook as an example of involving patients in research priority setting.

Abstract:

Health research priority setting processes assist researchers and policymakers in effectively targeting research that has the greatest potential public health benefit. Many different approaches to health research prioritisation exist, but there is no agreement on what might constitute best practice. Moreover, because of the many different contexts for which priorities can be set, attempting to produce one best practice is in fact not appropriate, as the optimal approach varies per exercise. Therefore, following a literature review and an analysis of health research priority setting exercises that were organised or coordinated by the World Health Organisation since 2005, we propose a checklist for health research priority setting that allows for informed choices on different approaches and outlines nine common themes of good practice. It is intended to provide generic assistance for planning health research prioritisation processes. The checklist explains what needs to be clarified in order to establish the context for which priorities are set; it reviews available approaches to health research priority setting; it offers discussions on stakeholder participation and information gathering; it sets out options for use of criteria and different methods for deciding upon priorities; and it emphasises the importance of well-planned implementation, evaluation and transparency.

To read the article, go to www.health-policy-systems.com/content/8/1/36.

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 want to express support for, be involved in or simply 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 323 Affiliates, most of which are listed on our website. Among these is Perspectives, Participation & Research, a team of researchers exploring how service users and clinicians see and can influence policy, practice and research. The team is part of the Social Science Research Unit at the Institute of Education, University of London, where staff engage in and promote rigorous, ethical and participative social research to support evidence-informed public policy and practice across a range of domains including education, health and welfare (see www.ioe.ac.uk/ssru). Sandy Oliver, Ruth Stewart, Jenny Caird and Kathryn Oliver, now at the University of Manchester, are long-standing affiliates of the JLA, and have made significant contributions to our work. They have



Seilin Uhm

reviewed published studies of patients and clinicians setting research agendas, offered independent reflections on a priority setting meeting and co-authored the JLA Guidebook. They are now joined by Seilin Uhm for a new JLA PSP for setting research priorities around very pre-term birth.

“There's so much in the media about tiny babies just now,” Seilin said. “It'll be exciting to find out what research would really help them, their parents and clinicians”. Sandy Oliver said that Seilin's research background in communication is already bringing benefits: “Within her first week she was engaging busy clinicians in discussions about research.”



Funding from the National Institute for Health Research, as part of a research programme led by obstetrics professor Lelia Duley, is being used to identify research questions considered important by both clinicians and service users; identify a 'core set' of outcomes for evaluating care during very pre-term birth; and investigate methods for clinicians and service users to work together, both face-to-face and at a distance. For further details, please contact Seilin Uhm on 020 7612 6532 or at s.uhm@ioe.ac.uk.



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 May 2011.

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