



Affiliates Newsletter – July 2011

MESSAGE FROM THE CHAIR

Dear colleague,

As we all strive to make our desks that little bit clearer before any summer break we are fortunate enough to have, it's a good time to take stock and think about what's important and what we do that makes a difference. Within the JLA we have a discipline of writing an annual review and you can find out more about it later in this Newsletter.

What strikes me most in reading this Newsletter though is the impact and difference individuals make. A Priority Setting Partnership (PSP) is simply a group of individuals who come together for a moment in time to do a job that they feel is important, often at their own cost and against an existing and demanding workload.

You will read about people who travel great distances, in adversity, to attend workshops where they hope to make a difference

You will read about one of our colleagues who set aside time to summarise her experiences into a 'toolkit' brimming with top tips on making patient and clinician participation more likely to succeed.

You will read of the death of Ann McPherson who, with Andrew Herxheimer, experienced a need and did something about it, which in turn led to a resource that helps thousands.

Within the JLA we are always enormously grateful for the enthusiasm and commitment of every single person who gets involved in the efforts of the JLA and PSPs because their work will make a difference to people they are never likely to meet.

Have a good break – and we look forward to working with and for you in the future.

Lester Firkins, Chair, James Lind Alliance



NEWS

Making the Difference: Patient and Public Involvement

The National Institute for Health Research Clinical Research Network (NIHR CRN) has launched a new publication emerging from its PPI Way Forward review. Edited by Derek Stewart, it gives clear examples of the application and impact of Patient and Public Involvement in the Clinical Research Networks. This is the first formal gathering of stories, examples and evidence that are specific to the NIHR CRN, and shows that the involvement of patients, carers and the public is making a difference in research. For further details, go to www.crncc.nihr.ac.uk.



Patient and Public Involvement Toolkit

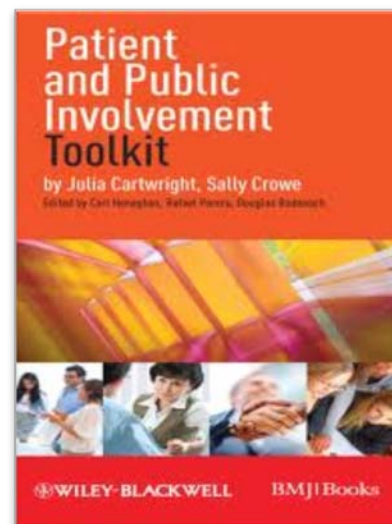
Written by Sally Crowe, Chair of the JLA's Monitoring & Implementation Group, and Julia Cartwright, Director of Flex Business Consulting, the *Patient and Public Involvement Toolkit* has just been published. This practical resource aims to help those involved in health care (whether clinician, service user or research commissioner) to undertake effective patient and public involvement (PPI) in their work. In fewer than 200 pages it addresses: the imperative for PPI; the practicalities of consulting and running workshops; building effective and inclusive relationships; and evaluating PPI. The Toolkit has been named Leeds University Centre for Innovation in Health Management's Book of the Month,



Sally Crowe

and in his blog, Simon Denegri, Chief Executive of Ovarian Cancer Action described it as "full of sound, practical advice in easy bite-sized chunks."

Linda Seymour at the National Institute for Health and Clinical Excellence (NICE) said: "The examples, case studies and web links are all invaluable. The whole book and its essence is one of facilitation with a strong message that the reader can do it too; it's not some secret society that only the initiated can comprehend. It should be required reading for every health – and also social care – practitioner." The *Patient and Public Involvement Toolkit* is available from Amazon and all good book retailers (ISBN: 978-1-4051-9910-0, price £16.99).



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

Type 1 Diabetes PSP is delighted to share its top 10 priorities plus its over-arching, long-term aspiration for research, which it identified at a workshop in May. These are as follows:



Overarching research aspiration: Is stem cell therapy an effective treatment/cure?

1. Is it possible to constantly and accurately monitor blood sugar levels, in people with type 1 diabetes, with a discrete device (non-invasive or invasive)?
2. Is insulin pump therapy effective? (*immediate v deferred pump, and comparing outcomes with multiple injections*)
3. Is an artificial pancreas for type 1 diabetes (closed-loop system) effective?
4. What are the characteristics of the best type 1 diabetes patient education programmes (from diagnosis to long term care) and do they improve outcomes?
5. What are the cognitive and psychological effects of living with type 1 diabetes?
6. How can awareness of and prevention of hypoglycaemia in type 1 diabetes be improved?
7. How tightly controlled do fluctuations in blood glucose levels need to be to reduce the risk of developing complications in people with type 1 diabetes?
8. Does treatment of type 1 diabetes by specialists (e.g. doctors, nurses, dieticians, podiatrists, ophthalmologists and psychologists) trained in person-centred skills provide better blood glucose control, patient satisfaction and self-confidence in management of type 1 diabetes, compared to treatment by non-specialists with standard skills?
9. What makes self-management successful for some people with type 1 diabetes, and not others?
10. Which insulins are safest and have the fewest *long term* adverse effects?

The next step is to bring these priorities to the attention of research funders, a task which the Steering Group is planning now. For information contact Sally Crowe on sally@crowe-associates.co.uk.

Ear, Nose and Throat – Aspects of Balance

The final priority setting workshop on this theme took place on 31st May, and the 10 priorities for research agreed by patients and clinicians are shown below. See page 7 for an interview with two of the workshop participants, to find out more about their experiences of the priority setting process and their aspirations for the top 10 uncertainties.



1. What is the optimal process for GP education and training for improved diagnosis and management of balance disorders?
2. What is the best way of training health professionals in the management of balance disorders?
3. What is the most effective treatment for vestibular migraine?
4. What are the best interventions to improve balance/minimise symptoms in daily activities such as supermarkets, escalators etc.?
5. Is any specific surgical intervention effective in Ménière's disease and what procedure is best?
6. Are there any effective interventions for the ear pressure symptoms in Ménière's disease?
7. What is the optimum pharmacological strategy for the management of patients with Ménière's disease? In particular, what are the effects of betahistine (including long term effects)?
8. Is it helpful in preventing the severity, frequency and progression of attacks of Ménière's disease to adopt a specific diet, or restrict salt, caffeine or fluid intake?
9. Are the home-based exercises given to patients with balance disorders effective?
10. Are stress management techniques helpful in patients with balance disorders?

If you would like any further information on this PSP, please contact Jo White jo@entuk.org.

Schizophrenia

The Schizophrenia PSP top 10 treatment uncertainties for research have just been published in an article in Nature (see page 9). These were identified by patients, carers and clinicians at a workshop in January. The full list is as follows:

1. What is the best way to treat people with schizophrenia that is unresponsive to treatment?
2. What training is needed to recognise the early signs of recurrence?
3. Should there be compulsory community outpatient treatment for people with severe mental disorders?
4. How can sexual dysfunction due to antipsychotic-drug therapy be managed?



5. What are the benefits of supported employment for people with schizophrenia in terms of quality of life, self esteem, long-term employment prospects and illness outcomes?
6. Do the adverse effects of antipsychotic drugs outweigh the benefits?
7. What are the benefits of hospital treatment compared with home care for psychotic episodes?
8. What are the clinical benefits and cost-effectiveness of monitoring the physical health of people with schizophrenia?
9. What are the clinical, social and economic outcomes — including quality of life and the methods and effects of risk monitoring — of treatment by acute day hospitals, assertive outreach teams, in-patient units, and crisis resolution and home treatment teams?
10. What interventions could reduce weight gain in schizophrenia?



Priority setting at the Schizophrenia PSP workshop

Members of the Steering Group are now working with the NIHR Health Technology Assessment programme to establish which questions might be suitable for funding. For further information, please contact Jo White: J.White@swansea.ac.uk.

Life After Stroke in Scotland

Bridget St George, Research Assistant at the Stroke Team at Glasgow Caledonian University, reports:

“The life after stroke in Scotland PSP is continuing the process of checking whether our submitted list of intervention questions are true uncertainties. We will then be forming a list of uncertainties under headings and subheadings and sending this out to our original contacts (stroke survivors, carers and clinicians). It may be necessary to personally visit some stroke clubs in order to assist those who, due to stroke-related difficulties, may find this task challenging. We will then be moving towards refining our list of uncertainties down to the all important 25 or



Bridget St George

so that will be taken forward to the consensus meeting later in the year.”



For further information, 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

This PSP led by ENT UK and Head and Neck 5000 has extended its deadline for gathering uncertainties until 30th November. For this PSP, as we have found in others, it is proving challenging to engage sufficient clinicians and patients to submit uncertainties. The Steering Group believes that there are more uncertainties to be identified and will take steps to encourage their submission after the summer break. This will involve much more personal contact and encouragement from the Steering Group on a one-to-one basis. Although labour-intensive, this approach has worked for others. This effort will be supported by a mail-shot to potentially interested parties, which we hope will include podcasts of presentations given at the first Awareness Meeting. For more information, please contact Jo White at Jo@entuk.org, or visit the JLA website:

www.lindalliance.org/HeadandNeckCancerJLAPrioritySettingPartnership.asp.

Pressure Ulcers

The Steering Group for this PSP met for the first time in July, in York. The group has representatives from a variety of organisations and individuals concerned with effective prevention of and treatment for pressure ulcers. These clinical and patient perspectives include spinal injury, multiple sclerosis,



tissue viability and older people in care and community settings. The partnership will shortly be advertising for a Project Support Officer. Anyone interested in this opportunity should contact Dr. Mary Madden (mary.madden@york.ac.uk). 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 Dr Madden (mary.madden@york.ac.uk) or Sally Crowe (sally@crowe-associates.co.uk).

Lyme Disease

"The Lyme Disease PSP has the kernel of a steering group so looks as if it may be able to move forward soon," says Stella Huyshe-Shires of Lyme Disease Action. "The survey is almost in its final form - all that is required is a little polishing and it will be ready for launch. Everyone is hopeful that this will be the start of a very productive process." Stella featured recently in an article in the Daily Telegraph, in which she and other Lyme disease patients described the challenges they face, both in terms of the condition and finding treatments. To read it, go to www.telegraph.co.uk/health/8511954/Deadly-Lyme-disease-on-increase-as-more-of-us-spend-time-outdoors.html. For further information on this PSP, please contact Stella.Huyshe@LymeDiseaseAction.org.uk.



Pre-term Birth

The aim of the Pre-term Birth PSP is to identify the unanswered questions about the effects of care and treatment for pre-term babies, as raised by service users and clinicians. Perinatal and neonatal interventions will be included, although prevention of preterm birth will be excluded. An initial partnership meeting was held on 14th July in London and was well attended by clinicians, service users and carers involved in pre-term birth and care. Two days previously, the team had presented a poster at the COMET (Core Outcome Measures in Effectiveness Trials) conference in Bristol. "There is great enthusiasm for the PSP," said Seilin Uhm, from the Institute of Education, who is coordinating the work. "The next step is to form a steering group from those partners who are particularly keen to help set priorities. I am keeping in touch with everyone who came to the workshop, and other organisations who could not be there. New members are still welcome."



Seilin Uhm and Sandy Oliver with their poster

For more information, please contact Seilin Uhm (s.uhm@ioe.ac.uk, 020 7612 6532) or visit the Pre-term Birth PSP website: <http://eppi.ioe.ac.uk/pretermbirth>.

Eczema

The Centre of Evidence Based Dermatology at the University of Nottingham, in collaboration with the JLA, is currently engaged in a survey to identify uncertainties about treatments for eczema and to prioritise them for future research. If you have any suggestions for topics that you think should be considered for future research into eczema treatments, please take time to complete the survey before the end of July. It is really important that we get a good response from clinicians, nurses and pharmacists as well as patients. You can find more information and access to the survey through the 'HOME' website at www.homeforeczema.org. For more information, contact Tessa Clarke, Senior Clinical Trials Development Manager: Tessa.Clarke@nottingham.ac.uk



Cleft Lip and Palate

The Cleft Lip and Palate PSP held a meeting on Saturday 11th June to introduce potential partners to the project. Almost 40 people attended, including adults with cleft, parents of children with cleft, and surgeons, nurses, dentists and speech therapists. Presentations included an introduction to the JLA, an overview of the aims of the PSP and an introduction to the UK Database of Uncertainties about the Effects of Treatments (UK DUETs). Small group discussions identified some initial uncertainties about the treatment, diagnosis and prevention of cleft, and participants also contributed their ideas for how the PSP can reach diverse groups to gather uncertainties. Rona Slator, plastic surgeon at Birmingham Children's Hospital said "This meeting was quite special. I attend many meetings about cleft lip and palate but I've never before been in this situation, where people with cleft lip and palate, parents and colleagues could come together to completely openly discuss the questions we all have about cleft." The PSP will be launching its uncertainties survey in September. For more information please contact Katherine Cowan: katherine@katherinecowan.net.



Publicising Partnerships and Priorities, by Sophie Petit-Zeman



Sophie Petit-Zeman

PSPs work hard to unite clinicians and patients to agree on research questions – no mean feat. But it's really important that their work doesn't end there. It's essential that potential funders get to know about what's been prioritised (to this end, JLA is working with DUETs to ensure that the "top 10" are flagged up there, and they will also go on the JLA website); academics will want to publish their results in peer-reviewed journals; and patients and carers may want to work with relevant charities to ensure the outcomes of JLA work gets into their newsletters. And all this is only a start: other possible dissemination routes include commentary articles in widely read journals, such as *Nature* (see page 9) and lay media – see for example: www.guardian.co.uk/society/2007/may/21/health.

In my day job as Adviser, Public Involvement & Engagement at the Association of Medical Research Charities (AMRC) I am closely involved with the business of the JLA through my membership of its Monitoring and Implementation and Strategy and Development Groups. But with another hat, having worked as a health and science journalist and medical editor for many years, I also work for the JLA for seven days a year as a communications consultant. If you have come to the end of your PSP – or, better still, are planning ahead – and would like advice on dissemination, or practical help with anything - from writing copy to figuring out whether your work might be of interest to a wider readership than you are used to communicating with - do get in touch: s.petit-zeman@amrc.org.uk; 01732 750 869.



ENT Aspects of Balance: what was the final workshop like?

The Ear, Nose and Throat (ENT) Aspects of Balance final priority setting workshop took place on 31st May 2011 at the Royal College of Surgeons in London and produced a top 10 list of patients' and clinicians' shared priorities for research. Katherine Cowan talked to two of the participants to find out what they thought of the day. Andrew Higgins is Editor-in-Chief of a veterinary journal and suffers from the balance disorder 'Migraine-Associated Vertigo'. Martin Burton is an ENT surgeon and a representative of ENT UK. They both sit on the ENT Aspects of Balance Steering Group.

How would you describe your experience of the final priority setting workshop?

Andrew: I found it very pleasing to see how engaged everybody was. All stakeholders, patients and clinicians, seemed to feel that here was an exceptional opportunity to focus on a much neglected area of human health. The bottom line will be to see whether we have been able to open the doors of funders of research and show them where research is really needed.



Martin Burton



Andrew Higgins

Martin: The thing that struck me most about it was, as Andrew said, the way in which everyone got engaged. We didn't have any 'passengers', everyone had a chance to participate. My overwhelming impression was one of discussion, debate and agreement, and at the end there was a sense that yes, this was a collective vision.

One aspect of a PSP that some people find hard to conceptualise is the mix of patients and clinicians in the discussions. Andrew, as a patient, what was your experience of that dynamic?

Andrew: The dynamic was surprisingly good. I felt that clinicians and patients realised they needed each other and I was very struck how much we all respected each other's opinions. The JLA facilitators did all they could to encourage people to contribute. Everyone's views were listened to very carefully and there was a surprising degree of mutual understanding. We all had a genuine sympathy for those with personal stories to tell, but the clinicians helped to keep everyone focused on the wider realities. People had made a real effort to get there, from all over the country. One clinician had come from Scotland and a number of patients came despite having serious balance disabilities. There was a passion and a drive there.

Martin, what was your view of the patient-clinician dynamic on the day?

Martin: I agree that it was good, but perhaps we shouldn't be surprised. It should always be the case that doctors and clinicians are prepared to listen to patients: it's part of our day-job. I think also when you have a self-selecting group of clinicians who are interested in a process like this, they are more likely to be this way. So those factors combined made it very collaborative.

Andrew: It is a sad fact that some patients have had experience of not making very much progress with members of the medical profession, but at the meeting there were professionals who were engaged, sympathetic and who listened; it was very refreshing.



Martin: There was a patient who'd travelled a long way to be there and was quite emotional at the end because he said he was so grateful to have had the opportunity to come. He was grateful that people had listened to him and he'd never envisaged himself at the Royal College of Surgeons. I was very moved by that. I think clinicians tend to underestimate the importance and the value of the opportunity for patients to participate in research priority setting.

Was there anything else about the workshop which you were struck by?

Andrew: I don't know about you Martin, but I was very impressed by the overwhelming agreement on the top priorities. We had a shortlist of 31, and I thought there would be far more debate. There was an unequivocal message which came out at the end of it: the absolute priority for educating GPs and health professionals to improve diagnosis and management of balance disorders.

Martin: I was impressed by how easily people seemed to be able to suspend their own personal enthusiasms. I thought we might have people determined to get 'their' particular issue on the list, but people seemed willing to listen to and understand other perspectives. We had a disproportionate number of people with Ménière's disease in the room, but in terms of influencing the list, it wasn't an issue. No one tried to steam-roller the process, which may be due to the JLA's chairing, or we may have simply been lucky that no one tried to dominate.

Andrew: I was conscious that my particular condition was fairly low down the pecking order of priorities, and I didn't want to plug it too much. I was grateful when one of the clinicians focused strongly on it, and persuaded others that it should be given more consideration.

What would you say you both got out of the day, either personally or professionally?

Andrew: As a patient, I had experienced difficulties in reaching a diagnosis so I got a lot of satisfaction being involved in the priority setting process and in highlighting some of the problems.

Martin: I have to take the outputs of the exercise, go back to colleagues and show them the list of priorities. I have some apprehension about how they will receive it, as the questions which have emerged are not your normal, 'hard' research questions. But I would argue to my colleagues that if that's what the patients want, then that's what we need to do. The proof will be in the pudding: if they're funded and then good answers come out that change practice, it will have been worthwhile.

What's happening with the top 10 priorities now?

Martin: The Steering Group is planning to turn the uncertainties into researchable questions and then distribute them to the various funding bodies, and I hope that the patient groups will send them back to their members as well.

Andrew, what are your aspirations for the top 10?

Andrew: My aspiration is that clear guidelines can be produced for primary and secondary care professionals so that they can deal in a methodical and effective way with patients who present with balance disorders. There needs of course to be an improvement in treatments and easier access to local advice with more specialist audio-vestibular therapy. Overall, I hope that we will have generated more interest in balance disorders. It's been a neglected area, so now let's move it forward.

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JLA Annual Report 2010-2011

The JLA's Annual Report for April 2010 to March 2011 is now on our website at www.lindalliance.org/JLA_Report_2010-2011.asp. During that period, we completed three PSPs, establishing top 10 lists of patients', carers' and clinicians' shared priorities for research in vitiligo, prostate cancer and schizophrenia. We also launched our Guidebook (www.JLAguidebook.org), a practical evidence-based guide to setting up PSPs. Not only is this an essential resource for all PSPs, it has also drawn national and indeed international attention to the work of the JLA. The JLA's profile has continued to grow. There were over 84,000 visits to the JLA website and the JLA Guidebook during the year. A re-launch of the Affiliate programme and application process saw Affiliate members increase by 74 per cent, bringing the total to 329. We also published two research reports: one exploring what happened after the completion of the Asthma PSP; and another to study patients' and clinicians' research priorities. Two event reports were also published, describing the outcomes of a meeting to consider industry's attitude to patient involvement, and another exploring opportunities to promote patient involvement in research prioritisation and commissioning. The JLA is grateful to our funder, the National Institute for Health Research (NIHR), whose support has enabled us to continue to deliver on this important agenda.

IN PRINT

Lloyd, K. and White, J. (2011) 'Democratizing clinical research', *Nature*, Vol. 474, No. 7351, pp. 277-278 (16 June 2011).

In this article, Professor Keith Lloyd and Jo White, from Swansea University's College of Medicine, describe the JLA's Schizophrenia Priority Setting Partnership. They examine the absence of patient and clinician involvement in health research priority setting, and argue for the value and benefit of that involvement, based on their experience of the JLA priority setting process. Presenting the top 10 list of patients', carers' and clinician's schizophrenia treatment uncertainties, the authors say: "We were involved in this exercise as clinical academics. This, plus our experience as recipients of grants and from within funding bodies, convinces us that money rarely goes to the studies that those with mental illness would choose. We therefore urge funders to adopt this list of top priorities for schizophrenia, and entreat other countries and organisations to use the technique involved in compiling it to steer other clinical research." To view the article and to find out more about the Schizophrenia PSP, go to www.lindalliance.org/JLASchizophreniaPSP.asp.



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 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 392 Affiliates, most of whom are listed on our website. One of our newest Affiliates is the British Tinnitus Association (BTA), the only national charity solely dedicated to supporting the tinnitus community. The charity seeks to encourage prevention and awareness through its educational programme, which includes its 'Talking Tinnitus' campaign and national 'Tinnitus Awareness Week'.



The BTA is seeking a cure for tinnitus through research and is fundraising for the extension of an existing clinical research project. The charity's 'Tackling Tinnitus' campaign, which highlights opportunities in tinnitus research, is striving to engage audiologists with the need for clinical research. This campaign has led the BTA to develop a JLA Tinnitus PSP, to promote the need for tinnitus research and to understand the priorities of patients and clinicians. There will be more information about this in the next Newsletter. The experienced team at the BTA operates a confidential freephone helpline on 0800 018 0527 and provides information at www.tinnitus.org.uk.

Remembering Ann McPherson, co-founder of www.healthtalkonline.org

Ann McPherson, a much loved and admired Oxford general practitioner, died from disseminated pancreatic cancer on 28 May 2011. Ann was special in many ways, and these have been touched on in laudatory obituaries in national newspapers as well as medical journals. The particular aspect of Ann's work which is and will remain of great relevance to people who identify with the objectives of the James Lind Alliance is that she co-founded – with Andrew Herxheimer – the Database of Individual Patient Experiences (DIPEX), now named healthtalkonline.



Dr Ann McPherson

Ann and Andrew established this award-winning website 10 years ago, after each of them had been patients, treated for breast cancer and osteoarthritis, respectively. They agreed that it was regrettable that there was no straightforward way through which someone facing treatment choices for a recently diagnosed health problem could find out about the experiences of people who had 'travelled those roads' previously. Together with social science



colleagues, healthtalkonline began to fill these gaps by assembling and publishing modules containing audio and video material as well as written text. These modules are free, and they currently cover over 60 health problems. In addition to drawing on people's experiences of health problems and treatment options, healthtalkonline points visitors to reliable sources of other relevant information.

Both as a professional and as a patient, Ann McPherson was clear that clinical research addressing treatment uncertainties should be an integral element of good health care. It is a reflection of this ethos that there are healthtalkonline modules based on the accounts of adult patients and the parents of children who have experience of clinical trials. A module on children's own experiences of clinical trials will follow. These are relevant to all readers of the JLA Newsletter, regardless of the particular health problems that may concern them.

Iain Chalmers

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 September 2011.

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