



## Affiliates Newsletter – September 2011

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### MESSAGE FROM THE CHAIR

Dear colleague,

I am delighted to enclose our September Newsletter, which really is bristling with updates on a variety of Priority Setting Partnerships (PSPs) in various stages of progress. This is our life-blood and we find that, as well as hopefully helping research funders target their spend right to the heart of the need (as agreed by patients and clinicians), they are also giving us a huge evidence base of how (and how not) to work in partnership. This can then be shared with other groups setting out on similar roads.

There are also some wonderful added benefits: at a recent PSP workshop, the executives of two patient support groups covering related conditions met, realised the synergy of their work and have since undertaken to work much more closely for mutual gain. And you will see how Thomas Kabir, a key partner in the Schizophrenia PSP, is continuing to work with us beyond research priority setting, to promote patient involvement in research itself.

You will also read that we are now “Tweeting” on Twitter. I always saw myself as an early adopter, but as age advances I get more apprehensive of pressing the green buttons on new stuff. Thanks to Katherine Cowan who has guided us through it, we are now getting real activity on this medium. In promoting PSPs in this way we are hoping that each one will have an increased level of participation and input. Do please follow us on Twitter (@LindAlliance) – you may be encouraged by what you see!

We did consider setting up a Facebook page as well, but that needs a much greater level of maintenance from an organisation – and as you know we are a small team (less than one full time equivalent), so for the time being will simply remain as Twits.

Thanks as ever for your support,

Lester Firkins, Chair, James Lind Alliance

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## NEWS

### JLA enters the Twittersphere: @LindAlliance

The JLA is now active on Twitter, the micro-blogging site, at [www.twitter.com/LindAlliance](http://www.twitter.com/LindAlliance). Katherine Cowan, Editor of the JLA Newsletter, will be managing the JLA's tweets, and would like to encourage all Affiliates who use Twitter to follow us: "I hope that Twitter will not only raise the profile of the JLA, but will also promote further debate online about the importance of involving patients, carers and clinicians in research priority setting," she said. "This will be another way for us to engage with a wide audience and raise awareness of the activities of our various Priority Setting Partnerships."



### Would you like to get involved with INVOLVE?

INVOLVE has a key national role supporting public involvement in NHS, public health and social care research. INVOLVE has around 30 members from a range of backgrounds and is looking for people with an understanding and experience of public involvement in research to join its Working Groups, including:

- members of the public, including patients and potential patients, carers, people who use health and social care services, disabled people;
- people from voluntary sector organisations that represent users of health and social services;
- people from NHS, local authority and research organisations with commitment and ability to promote public involvement in NHS, public health and social care research.

Three Membership Information Meetings will take place in October. Visit [www.invo.org.uk/Membership.asp](http://www.invo.org.uk/Membership.asp) for details and to download a Membership Information and Application Pack, or contact the INVOLVE Coordinating Centre: email [membership@invo.org.uk](mailto:membership@invo.org.uk) or telephone 02380 651088. The closing date for applications is 12 noon on Monday 31 October 2011.

# INVOLVE

### ICR & Cranfield launch second year of joint Clinical Research Fellowships

The Institute of Clinical Research (ICR) is offering fully-funded part-time Research Training Fellowships in partnership with Cranfield University. The Junior Fellowship will last two years and lead to an MSc by Research, while the Senior Fellowship will last four years and lead to a PhD. Applications are invited by October 31st 2011. For further information, visit [www.icr-global.org](http://www.icr-global.org).



## 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](http://www.JLAguidebook.org) or contact Patricia Atkinson ([patkinson@lindalliance.org](mailto:patkinson@lindalliance.org)).

### Type 1 Diabetes

Thanks to everyone who contributed to this PSP. The top ten priorities have been sent to relevant funders and research networks for initial feedback, and the Steering Group is meeting in October to review this feedback and progress priorities into proposals for research funding. Some Steering Group members have written a draft paper giving an overview of the priority setting process and results, and how these contrast with other priorities in diabetes research. This will be submitted for publication in a relevant journal later this year. Communicating the challenges, successes and outcomes of the PSP is an important part of next steps for partners and for the JLA. We are very grateful to partners who continue to give their time and expertise in this way. For information contact Sally Crowe: [sally@crowe-associates.co.uk](mailto:sally@crowe-associates.co.uk).



### Ear, Nose and Throat – Aspects of Balance

This PSP is now almost complete and the final touches are being applied to the top ten research priorities. An interesting development on this list will be the addition of suggested research routes to give potential funders a clearer idea of what the thinking was behind the uncertainty. Often the first step is to suggest that a systematic review is undertaken to determine precisely what is already known and its strength. This list will be published on our website soon. If you would like any further information on this PSP, please contact Jo White [jo@entuk.org](mailto:jo@entuk.org).



### Life After Stroke in Scotland

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



Alex Pollock

“Over the last few months we have worked hard to check and merge over 500 treatment uncertainties which were submitted to the Life After Stroke PSP. This resulted in 226 unique questions about the effects of treatments which have not yet been answered by research. To try to improve accessibility to the 226 questions, we categorised these under key headings. We are now in the process of asking stroke survivors, carers and health professionals to select their personal top 10 from this list of 226. We are doing this via post, email, attendance at professional meetings and by going to stroke clubs and groups. We had anticipated that selecting a personal top 10 from such a long list might be a challenge for some participants, particularly those with stroke-related difficulties relating to functions such as communication, vision and cognition. However we have been pleased to see that stroke survivors with a range of impairments have managed this task successfully, although we have found that some people were



able to choose 10 from the list but unable to rank these hierarchically. To see a copy of the 226 questions, please email Bridget St George ([Bridget.StGeorge@gcu.ac.uk](mailto:Bridget.StGeorge@gcu.ac.uk)).

“The date for our final consensus meeting is 16 November. We’re aiming for 20-30 participants at this event, half of whom will be stroke survivors and carers and half representing the relevant health professional groups. We’re looking forward to what we are sure is going to be an exciting (and challenging!) day.”

For further information, please contact: [Alex.Pollock@gcu.ac.uk](mailto:Alex.Pollock@gcu.ac.uk). Or go to [www.askdoris.org/D\\_JLA.asp](http://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 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](http://www.surveymonkey.com/s/Head_Neck_Cancer-Research_Priority_Setting_Partnership). The PSP held its initial awareness meeting in March, and videos of the speakers at this event can be viewed at [www.lindalliance.org/HeadandNeckCancerJLAPrioritySettingPartnership.asp](http://www.lindalliance.org/HeadandNeckCancerJLAPrioritySettingPartnership.asp).

For more information, please contact Jo White at [Jo@entuk.org](mailto:Jo@entuk.org).

### Pressure Ulcers

The Steering Group for this PSP 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. Currently a survey is being piloted in a spinal injuries unit and it is hoped that a Project Support Officer will be in place to move the work on by the time the Steering Group next meets in November. The partnership was featured in an article in the journal of the European Wound Management Association (see In Print, below), and was invited to speak at a pressure ulcer prevention conference in July.

Wounds research  
for patient benefit

To keep up to date with progress, visit the PSP’s website [www.jlapressureulcerpartnership.co.uk](http://www.jlapressureulcerpartnership.co.uk). For further information on the next stages please contact either Dr Madden ([mary.madden@york.ac.uk](mailto:mary.madden@york.ac.uk)) or Sally Crowe ([sally@crowe-associates.co.uk](mailto:sally@crowe-associates.co.uk)).

### Lyme Disease

The Lyme Disease PSP has launched its survey. To take part go to [www.lymediseaseaction.org.uk/jla](http://www.lymediseaseaction.org.uk/jla). “The survey is going well so far. Several Local Medical Committees across the country have agreed to publicise the survey in their newsletters, so we hope that will generate more contributions from GPs. If anyone can raise the survey with rheumatology, neurology or infectious disease colleagues it would help tremendously” says Stella Huyshe-Shires of Lyme Disease Action. To date, 112 respondents have taken part and between them submitted 263 raw (ie unchecked) uncertainties about the diagnosis and treatment of Lyme disease.



Over half are adults with or who have had Lyme disease, and over a third are clinicians working in primary care. For further information on this PSP, please contact [Stella.Huyshe@LymeDiseaseAction.org.uk](mailto: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.

“This PSP is up and running,” reports Seilin Uhm. “Issue two of our newsletter and a report from the first priority setting workshop, which took place in July, are now available at <http://eppi.ioe.ac.uk/pretermbirth>. For those who missed it there are provisional arrangements for a repeat workshop to take place on 14 November at the University of Nottingham. The first Steering Group meeting will be held the same day. In response to the recommendations from partners, the Preterm Birth PSP will be using Facebook and Twitter (@PretermBirth)”.



For more information, please contact Seilin Uhm ([s.uhm@ioe.ac.uk](mailto:s.uhm@ioe.ac.uk), 020 7612 6532) or visit the Preterm 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, has closed the survey to identify uncertainties about treatments for eczema. The response was phenomenal: over 400 respondents each suggesting up to five uncertainties, bringing in a total of 1100 research uncertainties. The team is now engaged in processing the data and drawing a long list of research uncertainties to be prioritised. You can find more information about the partnership through the ‘HOME’ website at [www.homeforeczema.org](http://www.homeforeczema.org). For more information, contact Tessa Clarke, Senior Clinical Trials Development Manager: [Tessa.Clarke@nottingham.ac.uk](mailto:Tessa.Clarke@nottingham.ac.uk)

### Cleft Lip and Palate

Over 1000 infants are born every year with a cleft of the lip and/or palate. These babies often require several operations and lots of other healthcare interventions, including hearing tests, speech therapy, dental care, orthodontic treatment and psychological support. However there remain lots of unanswered questions about clefting. The aim of the Cleft Lip and Palate PSP is to find out which questions about clefting patients, carers and clinicians most want answered.



The Cleft Lip and Palate PSP, supported by the Craniofacial Society of Great Britain and Ireland, launched its survey at the Cleft Lip and Palate Association (CLAPA) conference on 10



September. To see a video of Rona Slator explaining the importance of this PSP, and the uncertainties which surround cleft lip and palate, go to [www.vimeo.com/29111443](http://www.vimeo.com/29111443). If you have an unanswered question about clefting, please participate at [www.clapa.com/survey](http://www.clapa.com/survey). Alternatively you can email [info@clapa.com](mailto:info@clapa.com) for a copy of the survey, or call 020 7833 4883 to respond over the phone. The survey will remain open until 31 November 2011. For more information please contact Katherine Cowan: [katherine@katherinecowan.net](mailto:katherine@katherinecowan.net).



## What do you need to involve people in research?

By Thomas Kabir, Coordinator, NIHR Mental Health Research Network (MHRN) Service Users in Research



What would a researcher actually need to involve a patient in his or her research? Broadly speaking, I think that you would basically need five things: **people**, **purpose**, **time**, **money** and **forms**. In this short article, I will go through each of these five areas to pick out some resources that I think might be useful.

### People

The first thing that you might need is people to involve in the first place. *Where could you find people to get involved in research?* Thomas Kabir

- *Your or your colleagues' patients.* You may well have a group of patients who have exactly the condition you are interested in right under your nose!
- *Through medical charities.* Most medical charities have local or national groups of patients. In the UK the Association of Medical Research Charities ([www.amrc.org.uk](http://www.amrc.org.uk)) is a good starting point to find a medical charity.
- *Through advertising.* INVOLVE ([www.invo.org.uk](http://www.invo.org.uk)) has an excellent website called People in Research ([www.peopleinresearch.org](http://www.peopleinresearch.org)).

### Purpose

It is important to be clear with people who you involve, what you would like them to actually do. All too often patients who get involved in research struggle because they don't know quite what is expected of them. Filling out an involvement agreement can help prevent these kinds of problems. For an example, go to [www.mhrn.info/data/files/FOR\\_RESEARCHERS/Toolkit/5\\_Sample\\_involvement\\_agreement.dot](http://www.mhrn.info/data/files/FOR_RESEARCHERS/Toolkit/5_Sample_involvement_agreement.dot).

Ways in which people can get involved in research are:

- Reviewing patient information sheets and consent forms for readability. My organisation, the MRHN, already offers this service for free to mental health researchers: [www.mhrn.info/pages/fast-r-service.html](http://www.mhrn.info/pages/fast-r-service.html).
- Commenting on a research proposal before an application for funding is made.
- Helping to actually carry out aspects of the research itself, such as interviews.
- Disseminating the findings of research and helping put it into practice.

INVOLVE has produced an excellent publication entitled *Senior Investigators and Public Involvement* which gives a number of really clear examples of how senior researchers have involved people in their research and the difference that their involvement has made: [www.invo.org.uk/pdfs/SIFINALPAPERNOV2009101109.pdf](http://www.invo.org.uk/pdfs/SIFINALPAPERNOV2009101109.pdf).

### Time

This is very important. You will need to be able to take the time to explain your research in a plain and non-technical way to the people who you involve, and to answer their questions. These people may not have the years of training that undertaking a research qualification requires. It is important that you set aside some time to go through things with them before meetings. In my experience it also helps to give people the contact details of someone within the research team who can answer questions at other times and act as a general point of contact. See the MHRN's template here:

[www.mhrn.info/data/files/FOR\\_RESEARCHERS/Toolkit/6\\_Sample\\_contact\\_sheet\\_for\\_service\\_user\\_advisor.dot](http://www.mhrn.info/data/files/FOR_RESEARCHERS/Toolkit/6_Sample_contact_sheet_for_service_user_advisor.dot).

### Money

Involving people is likely to cost money. A lot of people who might get involved in research are ill and/or unemployed and simply can't afford to be involved unless their travel costs (at a minimum) are covered. Even if you can't pay people very much, a small gesture, such as providing someone with a meal, can really make them feel valued.



## Forms

Nobody likes forms, but they can be useful and even necessary. If you want to involve people in research then you might need to produce an advertisement, give people an application form to fill in (this will help you choose the right people to involve if you get a lot of applicants), a role description, and so on. The MHRN has produced a 'Toolkit' for researchers with a whole set of open access pro-forma documents that you can use and change, as needed: [www.mhrn.info/toolkit](http://www.mhrn.info/toolkit). It also contains lots of useful contacts and references.

I'm no expert and I do not pretend that this article even covers the basic issues that you might need to consider when involving people in research. But I do hope that it is a start and that you will find it useful.

For more information, go to [www.mhrn.info/toolkit](http://www.mhrn.info/toolkit) or contact [thomas.kabir@kcl.ac.uk](mailto:thomas.kabir@kcl.ac.uk).

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## What problems need new treatments? Any ideas for new treatments?

By Sandy Oliver, Professor of Public Policy, Social Science Research Unit and EPPI-Centre, Institute of Education, University of London.

So far the JLA has focused on unanswered questions about the effects of treatments. Patients and clinicians may also have useful suggestions for research about developing treatments. We need research that builds on our understanding of health and disease to develop treatments, not just to test their effects. This is sometimes called 'bench to bedside' medical research. Where our understanding comes more from health surveys, it might be more appropriately called 'survey to social support', or from electronic patient records where it might inspire developments from 'e-health to public health'. Whether based on our understanding of the human body, communities or populations this is all 'translational research' leading to medical treatment, social care or public health policy.



Sandy Oliver

Do patients and clinicians have something to say about research for developing treatments? Do they (or you) understand health and disease in ways that could suggest the most important problems or the most promising areas for developing treatments? Do they (or you) have something to say about how to involve patients and clinicians in setting priorities for research about developing treatments?

It's taken me a while to understand what 'translational research' is. Now I'd like to understand it from the perspective of patients and clinicians, and learn how to engage patients and clinicians in debates and priority setting about developing treatments.

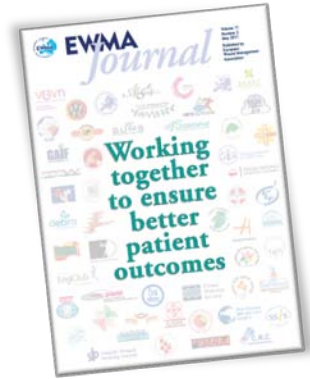
Please do send me your ideas, whether you are a patient, clinician or researcher.

[s.oliver@ioe.ac.uk](mailto:s.oliver@ioe.ac.uk) @profsandyoliver



## IN PRINT

Lamb, K., Stubbs, L., Dumville, J., Cullum, N. and O'Meara, S. (2011) 'Wounds Research for Patient Benefit: A five year programme of research in wound care', *European Wound Management Association Journal*, Vol. 11, No. 2, May 2011, pp. 43-46.



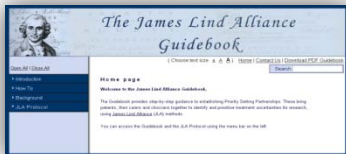
This article describes the Wounds Research for Patient Benefit (WRPB) programme, which started in 2008 and will receive £1.75 million of funding from the Programme Grants for Applied Research funding stream of the NIHR, over five years. The research programme is a multidisciplinary collaboration between NHS Leeds Community Healthcare and the University of York, and includes a JLA priority setting process, in order to understand what matters most to patients, carers and health professionals in complex wound care. To read the full article, go to

[http://ewma.org/fileadmin/user\\_upload/EWMA/pdf/journals/Journal\\_2\\_2011\\_WEB.pdf](http://ewma.org/fileadmin/user_upload/EWMA/pdf/journals/Journal_2_2011_WEB.pdf)

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## ON THE WEB

Stay up to date with our work at [www.lindalliance.org](http://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](http://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](http://www.twitter.com/LindAlliance).



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## 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](http://www.lindalliance.org/Affiliates-Programme.asp) to sign up.

The JLA currently has 413 Affiliates, most of whom are listed on our website. Richard Wormald is one of our newest individual Affiliates:





Richard Wormald

“As coordinating editor of the Cochrane Eyes and Vision Group, I am acutely aware of the paucity of evidence supporting many interventions in eye care and the saving of sight. Nearly 25 per cent of our reviews are empty – ie could find no trials of sufficient quality – to answer questions of clinical importance. This includes many common and blinding conditions. The surgical dominance of the specialty is to some extent to blame, but there is also an illusion of objectivity for outcomes which can be measured optically or in some other physical form that allows clinicians to forget about the patient’s experience. Until recently their views have been ignored. Vision 2020 UK is the British contribution to the WHO’s global initiative for the elimination of avoidable blindness by 2020. A key part of this is to engage with patients and carers to produce a list of research priorities which can be used for raising substantially more funding for eye research which will target their concerns and steer research teams to focus on those needs.” [www.vision2020uk.org.uk](http://www.vision2020uk.org.uk)



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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 November 2011.

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