



**Affiliates Newsletter – November 2012**

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**MESSAGE FROM THE CHAIR**

Dear colleague

The entire JLA crew has just returned from an excellent INVOLVE Conference (crew being Sally, Katherine, Patricia and me!)

The keynote speaker for Day One was Sir Iain Chalmers. Iain spoke about many things, but focused particularly on the avoidance of waste in research and the role that the JLA plays in that reduction. You can access Iain's slides online at [www.invo.org.uk/blog/sir-iain-chalmers-keynote-address-powerpoint-presentation-now-available/](http://www.invo.org.uk/blog/sir-iain-chalmers-keynote-address-powerpoint-presentation-now-available/).

The JLA was fortunate to be given a workshop session on Day Two where four of our Priority Setting Partnerships (PSPs) shared specific elements of their respective processes, including the use of social media and activity following the identification of research priorities. This was very well received by a packed room – such a contrast to our early years when often the speakers outnumbered the audience! This session was recorded, and when the link becomes available, we will be sure to share it with you.

It has become clear that the word is out concerning our migration to the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC) in April: our in-box is dominated by requests for chats about potential new PSPs. Please be assured that post-March we will still be very much open for business. By then we will have appointed additional JLA Advisors following the procurement exercise by NETSCC.

Thanks, as ever, for your support – and of course, we all wish you a peaceful and rewarding Christmas.

Lester Firkins, Chair, James Lind Alliance

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## NEWS

### New resources from INVOLVE

INVOLVE, the patient and public involvement in research organisation, has been asked by the Department of Health to work with the National Institute for Health Research (NIHR) Programmes and other key stakeholders to improve the quality of plain English summaries for NIHR-funded research. This will include reviewing and developing the question and guidance for plain English summaries in grant applications, and developing criteria and methods for assessing the quality of those summaries. In addition, INVOLVE has produced a new supplement, *Public involvement in systematic reviews: supplement to the briefing notes for researchers*. Aimed at researchers who carry out systematic reviews, the information can be downloaded from [www.invo.org.uk](http://www.invo.org.uk).



### Critical Appraisal Skills Programme (CASP): Making sense of evidence

How can you tell whether a piece of research has been done properly and that the information it reports is reliable and trustworthy? How can you decide what to believe when making a health care decision, when research on the same topic comes to different conclusions? This is where critical appraisal skills help. Critical appraisal skills enable you to assess the trustworthiness, relevance and results of published papers so that you can decide if they are believable and useful. CASP workshops bring together a multi-disciplinary group of people such as GPs, consumers, purchasers and providers, which promotes collaboration and develops a common desire to work together to get research evidence of effectiveness into practice. Using friendly and interactive approaches and trusted learning resources, CASP will be running the following workshops in the New Year:



#### CASP: Introduction to critical appraisal

1. Making sense of systematic reviews (AM: 9:00 – 12:30)
2. Randomised controlled trials (PM: 13:30 – 17:00)

Wednesday 16th January 2013 at Kellogg College in Oxford

£99 +VAT per half day workshop including refreshments and materials, or come to both sessions for a reduced price of £180 +VAT.

#### CASP: for Consumers

This interactive workshop aims to help consumers develop the skills needed to make sense of scientific evidence.

Wednesday 23rd January 2013 at Kellogg College in Oxford (PM: 13:00 – 16:00)

£99 +VAT per workshop including refreshments and materials

#### CASP International Training Week

18th- 22nd March 2013 at Kellogg College in Oxford

£996 + VAT for five days of workshops including refreshments, two-course daily lunch and materials

If you would like any more information or would like to book please contact: [Ruth.Brice@casp-uk.net](mailto:Ruth.Brice@casp-uk.net) or see [www.casp-uk.net](http://www.casp-uk.net), or follow on Twitter @CASPUK.



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

### Childhood Disability Research

Chris Morris, Senior Research Fellow in Child Health at the Peninsula Medical School, reports: "The Steering Group has been finalised with two further parents recruited through the National Network of Parent Carer Forums joining us since we first met. The website has been revised with feedback from several parents in the Peninsula Cerebra Research Unit for Childhood Disability Research (PenCRU) Family Faculty in an effort to ensure the aims and purpose are widely understandable. The Steering Group is in the final stages of preparing a list of potential partner professional and family support organisations to be invited to participate. Given the impending holiday period it is likely that the survey to gather ideas and uncertainties will be launched in earnest early in 2013."



Chris Morris

For more information, go to [www.bacdis.org.uk/research/psp.htm](http://www.bacdis.org.uk/research/psp.htm).



### Cleft Lip and Palate

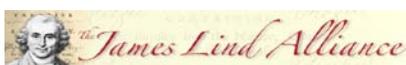
Sponsored by the Craniofacial Society of Great Britain and Ireland (CFSGB&I) and the Cleft Lip & Palate Association (CLAPA, the UK charitable organisation supporting families affected by cleft), the Cleft Lip & Palate PSP held its final priority setting workshop in Birmingham on 20th October. This face-to-face workshop attracted equal numbers of people affected by cleft, their carers/parents and clinicians to come together to agree a shared list of priorities for research. This PSP was the first to embrace uncertainties not just about treatment but also the cause of, and outcomes associated with, being born with a cleft. The decision to be inclusive was born out by the breadth of the topics included in the final list – a top 12 (see below).



Rosanna Preston

"I must admit to some nerves beforehand," said Rosanna Preston, Chief Executive of CLAPA and member of the PSP Steering Group. "On the day though, the process worked very well. Everyone came with strong beliefs and opinions which they were prepared to defend, but at the same time people were willing to listen to argument and be persuaded. I genuinely feel that it is the best example of user involvement that I have been a part of – it was great to be able to take a step back and let people who are personally affected by these issues argue

their case. It was also great to see that they had discussed the issues with other families before the meeting and that they felt really personally invested in getting the right list of priorities. It was also good to see patients/parents and clinicians talking on equal terms, and patients feeling able to challenge clinicians and tell them what is really important to them about cleft care. I know the clinicians found this healthy as well. I think we have a real responsibility to circulate these questions as widely as possible now and to do what we can to ensure that researchers pick them up."





Ana Dart

Ana Dart was one of the parents taking part in the workshop. She said: "It was a pleasure to be part of the JLA meeting. To have participated in a process that will provide some help towards answering such important questions was unique and something I am proud of. Throughout the whole process we, as parents, were treated as equal with professionals, given time to air views and opinions without prejudice. Admittedly I am fairly confident in speaking about things I feel passionate about, however, as my daughter's surgeon was present, I did think I might not feel comfortable saying anything negative about my own experiences, or research I felt strongly about. I need not have worried as the set up of the

groups and discussions were well managed and everyone was heard. Hearing other viewpoints from all over the cleft community was a highlight. I would not hesitate in participating again."

Paediatric Dentist and Steering Group member Nicky Kilpatrick said "This is the culmination of an exciting project which, thanks to the rigour and transparency of the JLA methodology, has fostered strong and enthusiastic engagement across the cleft community. Not only does this PSP contribute further to the very exciting research strategy that is evolving in the UK, but it has also drawn patients and their families into closer partnership within this strategy. There is a plethora of learning arising from this PSP and we will be working to make this widely available in due course."



Nicky Kilpatrick

**The 'top 12' priorities for research in cleft lip and palate**

1. What types of psychological intervention (individual therapy, community or school based) and at what time (from diagnosis to adulthood) are most helpful for patients with a cleft of the lip and/or palate and their families?
2. What are the educational, employment and personal (eg relationships) outcomes for individuals with a cleft of the lip and/or palate during childhood, adolescence and in the long term?
3. What is the best protocol for primary repair of both the lip and palate, including technique/timing and sequence?
4. In individuals with a cleft of the lip and/or palate when is the most effective age to begin speech therapy?
5. What is the best treatment for otitis media with effusion (glue ear) in individuals with a cleft of the lip and/or palate?
6. Can stem cells be used to improve palate repair (both primary and secondary)?
7. What interventions would enhance the educational outcomes for children with a cleft of the lip and/or palate?
8. What is the impact of having a baby born with a cleft of the lip and/or palate on maternal/child attachment?
9. What is the best way to manage infants with a cleft of the lip and/or palate undergoing primary surgery before, during and after hospital Eg. Fluids, pain control, antibiotics, probiotics, arm splints, feeding practices?
10. What are the genetic and environmental causes of clefts of the lip and/or palate?
11. How can we improve the diagnosis of cleft palate (without cleft lip)?
12. What is the best way to prevent tooth decay in children with a cleft of the lip and/or palate?

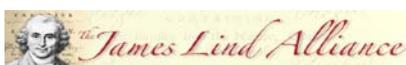
**Dementia**

Sarah Kelly from the Department of Public Health & Primary Care at Cambridge University has begun



Sarah Kelly

reviewing the submissions. She says: "The Dementia PSP received over 1563 completed surveys in the final count, from which there were over 4000 submissions about prevention, treatment, diagnosis and care of dementia covered by the questionnaire. Many of the submissions contained multiple questions so it is anticipated that there will be a large number of questions in our initial 'long list' of questions. The data have been categorised into themes and we are now working through the process of removing submissions that are out of scope (in discussion with the Steering Group), combining duplicate and similar questions, and formatting PICO questions (questions containing reference to the Patient or Problem, Intervention, Comparator and Outcome). Research recommendations



relating to dementia from NICE guidelines and Cochrane systematic reviews have also been sourced and included. We aim to have identified our initial list of questions by January. After that the questions will be checked against existing systematic reviews to identify which questions are true uncertainties to be put forward for the prioritisation process.”

For more information please visit the Alzheimer’s Society website at [www.alzheimers.org.uk/dementiaps](http://www.alzheimers.org.uk/dementiaps) or contact Nicola Hart at [Nicola.Hart@alzheimers.org.uk](mailto:Nicola.Hart@alzheimers.org.uk) or Sarah Kelly at [sak65@medschl.cam.ac.uk](mailto:sak65@medschl.cam.ac.uk).

### Dialysis (Canada)

Erin Lillie, Research Coordinator at the Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, writes with news of a Canada-based PSP working in association with the JLA: “We are asking people on dialysis, their care providers and the clinicians who look after them to share their ideas about the research that they think is needed to help improve the management and quality of life of people on dialysis. Participation involves completing a short, anonymous survey, which can be accessed directly at:

<http://fluidsurveys.com/surveys/drbarnieh/cann-net/langeng/>. The survey asks respondents to identify questions about diagnosis, prognosis (prediction of how things may develop in the disease), treatment, and anything else that they think should be studied through research. More information about this survey is available at [www.cann-net.ca](http://www.cann-net.ca). This study is supported by the Kidney Foundation of Canada and the Canadian Institutes of Health Research.”



Erin Lillie

### Multiple Sclerosis



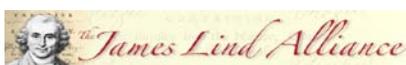
Mital Patel

“Multiple sclerosis (MS) is a neurological condition”, writes Mital Patel of the MS Society. “Around 100,000 people in the UK have MS and a further two million are affected by it in some way. Until now MS research has been an open playing field of topics, with an almost limitless choice of potential projects to fund. The MS Society wants to change this. We want to produce a list of research questions that reflect the priorities of people affected by MS and the health professionals to whom they look for help.

“On 25 July, the MS Society and the JLA held a meeting in London with those interested in setting up an MS PSP. After a successful meeting, a Steering Group was formed and a protocol agreed. Partners include people with MS, the UK MS Specialist Nurses Association (UKMSSNA), the MS National Therapy Centres, the Association of British Neurologists (ABN), and an MS Specialist Nurse, Consultant Neurologist and an Independent Information Specialist. This new partnership has adopted a wide scope and aims to identify unanswered questions in MS research. These could include any area of MS, from treatments for a particular symptom to support for day-to-day life with MS. The resulting priorities will inform the MS Society’s research strategy and it is also hoped that other funders will consider these priorities when reviewing applications or setting strategic research aims. We launched our survey on 1st November and hope to identify a top ten list of priorities by May 2013.”



For more information and to take part in the survey, please visit the MS PSP website: [www.mssociety.org.uk/jla](http://www.mssociety.org.uk/jla).



## Pressure Ulcers

Richard Morley, Project Support Officer for the Pressure Ulcer PSP at the Department of Health Sciences, University of York, writes:

“The James Lind Alliance Pressure Ulcer Partnership (JLAPUP) has recently completed its online and paper prioritisation surveys. These were promoted widely at events in Yorkshire. Paper versions were distributed through NHS sites in Leeds and York and social media was extensively used to promote the survey, including creating YouTube footage to explain the survey

([www.youtube.com/watch?v=Cw4DhnWwnjc&feature=youtu.be](http://www.youtube.com/watch?v=Cw4DhnWwnjc&feature=youtu.be)). One hundred and seventy three people took part online and on paper. We are presently analysing the results. Our next stage is to bring patients, carers and health professionals together to discuss their priorities in the light of the survey results.

We are presently planning our involvement in World Stop Pressure Ulcers Day. Our final prioritisation workshop will be at the end of March 2013.”



Richard Morley

For further information go to [www.jlapressureulcerpartnership.co.uk](http://www.jlapressureulcerpartnership.co.uk) or follow @JLAPUP on Twitter.

## Preterm Birth

Seilin Uhm reports: “In early November the Steering Group met in London at the office of charity Bliss. Members were delighted that over 1000 people visited



**NIHR Programme Grant**

Improving quality of care and outcome at very preterm birth

the survey and around 500 research questions were collected. However, most of these responses were from white, middle-class and well-educated people, and do not represent the diversity of families experiencing preterm birth. The Steering Group has therefore decided to promote the survey extensively to people from ethnic minorities and disadvantaged groups. The new deadline for



Seilin Uhm

this targeted part of the process is 31st December. At the meeting, Steering Group members agreed on the final version of the PSP’s Protocol. They also reviewed early findings from the survey. The research questions about preterm birth will be categorised chronologically (pre-pregnancy, antenatal, perinatal, postnatal care at hospitals, postnatal care after discharge, childhood and adulthood). A ‘long list’ will be produced by March 2013 and voting for priorities will take place from mid-April to mid-May. The most important research questions (based on the outcomes of the voting) will be decided at the May Steering Group meeting. The PSP will invite all partners to the final workshop to discuss detailed research questions and recommendations for future research. The final workshop is scheduled on the 11th June 2013 at Institute of Education, University of London.”



Steering Group members

The Preterm Birth PSP Protocol and the meeting reports can be found at <http://eppi.ioe.ac.uk/pretermbirth>. For further details, or to get involved, visit the website or contact Seilin Uhm ([s.uhm@ioe.ac.uk](mailto:s.uhm@ioe.ac.uk), 020 7612 6532, or on Twitter @PretermBirth).

## Sight Loss and Vision

Dr Dolores Conroy, Director of Research at Fight for Sight, writes: “Our Data Assessment Group is continuing to analyse the 4461 questions generated as a result of the Sight Loss and Vision PSP survey. The starting point has been to ensure that the questions fall within the scope of the exercise





Dolores Conroy

and then to categorise the questions into groups of eye diseases/conditions. This has now been completed for age-related macular degeneration (AMD) (842 questions) and glaucoma (1315 questions), and the analysis of cataract questions is almost complete. The questions for the other categories of eye diseases/conditions are currently being analysed. Relevant up-to-date published systematic reviews of research evidence are now being checked to ensure that the questions related to AMD and glaucoma represent uncertainties and this will also be done for the other groups of eye diseases/conditions. It is expected that the interim prioritisation exercises will take place in January-March 2013 and this will be followed by the final prioritisation exercises. It is expected that the results of the PSP will be reported by mid-2013.”

If you would like to know more about the Sight Loss and Vision PSP, please visit [www.sightlosspsp.org.uk](http://www.sightlosspsp.org.uk) or contact Dolores at Fight for Sight on 020 7264 3900 or email [sightlossandvisionpsp@fightforsight.org.uk](mailto:sightlossandvisionpsp@fightforsight.org.uk).



**Dystrophic Epidermolysis Bullosa (DEB) PSP: the JLA method adopted in Spain**

*The JLA Guidebook has been used to carry out a priority setting process in Spain for a chronic skin condition. Ignacio Doval, dermatologist and epidemiologist from the Spanish Academy of Dermatology, explains.*

Over the last year we've been working on a Dystrophic Epidermolysis Bullosa (DEB) PSP. Following a previous collaboration, the Research Unit of the Spanish Academy of Dermatology and DEBRA Spain, a patient association, decided to follow the JLA methods to prioritise research for this disease. We knew it was going to be a difficult task, as DEB, with a prevalence of just six cases per million in Spain, is a very rare disease, but we also knew that it was a study really needed for patients.

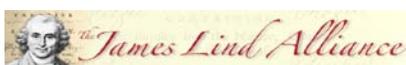
DEB is one of the most severe forms of a genetic condition in which the skin and internal body linings blister at the slightest knock or rub ([www.debra.org.uk](http://www.debra.org.uk)). In severely affected patients the disease causes not only skin problems including a high risk of cancer, but a plethora of other complications, such as problems when eating, defecating or maintaining hand and feet functionality. With so many different symptoms, as well as complications which cause severe disability, and a limited budget for research, prioritisation was a must.

We asked 125 patients and 29 health care professionals for uncertainties. We had a 30 per cent response rate from patients and carers and a 59 per cent response rate from professionals, including nurses, doctors, surgeons, a dental practitioner, an expert in orthopedic problems in DEB and a psychologist. We updated a previous systematic review, and with the help of Mark Fenton (Editor, UK Database of Uncertainties about the Effects of Treatments – UK DUETs) and the JLA's Sally Crowe, and we transferred our uncertainties into UK DUETs.

After a round of voting to rank the uncertainties, we had our final prioritisation workshop on 19th October in Madrid. It was a really enriching experience, both on a professional and personal level. We used the methods proposed by the JLA (nominal



Small group discussions, including one participant contributing online via Skype



group technique). We had three patients (of different ages and gender), two carers, one psychologist, two nurses, three doctors (from the Spanish Academy of Dermatology), and a representative of DEBRA Spain, as well as the help of three facilitators. It was surprising that the level of agreement among participants was very high for the initial proposals, before any discussion had taken place. About 15 uncertainties (of 24) got all the votes in the first round (in the three groups). However it took the whole group several hours to select the final 10 uncertainties.

Some of the things we learned might be interesting for other groups doing PSPs. For example, the final discussion was long and challenging, and three uncertainties, previously considered different, were merged at the time of selecting the top 10. Questions about topical care (bath frequency, use of antiseptics, wound care frequency) are strongly related and are likely to be grouped if research is planned, so we considered all of them as a single topic. We will provide more detail in the final paper. Also, our PSP was focused on a very rare and severe disorder, and we used a quite stringent definition for experts: they had to be professionals directly treating more than 10 patients. We therefore had some problems getting an adequate number of participants present at the final workshop. One doctor was in San Francisco and one patient, who lived 500km away, suffered recent trauma and could not come. Both had to participate online (using Skype), and although we were uncertain about how it would work, it worked very well, both in the small groups and in the final general meeting. With the help of facilitators they were able to give their views on the discussions (in fact both were very active). When asked about their impressions after the meeting, they said that they did not feel isolated or had any trouble following the discussions.



The workshop participants

Overall, this was a very satisfactory experience, and we hope that it will help getting the most out of the limited budget for research in DEB.

For more information, contact Ignacio Doval at [ignacio.garcia.doval@aedv.es](mailto:ignacio.garcia.doval@aedv.es).

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## Update on the transition of the JLA to NIHR Evaluation, Trials & Studies Co-ordinating Centre (NETSCC)

Sarah Fryett, Senior Programme Manager, NETSCC, JLA

We are making good progress towards migrating the JLA to NETSCC in April 2013. Our work at the moment is beginning to focus on the detail and understanding the day to day working of the JLA and its advisers.

### PSPs

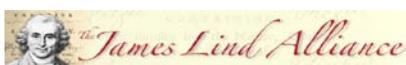
I recently observed the final priority setting meeting of the Cleft Lip & Palate PSP, which was a really interesting day. Whilst it was everything I expected it to be, it was good to see priority setting 'in the flesh' and I was impressed by the enthusiasm and commitment of every single participant in the workshop. Whilst consensus decision making has its flaws and challenges, it was great to see everyone being able to make their contribution to come up with a top 12 (in this case!) that represents key uncertainties in this area. I am also looking forward to observing the initial awareness meeting of the forthcoming Inflammatory Bowel Disease PSP at the end of November to see how the process begins.



Sarah Fryett

### Affiliates' Contacts Data

One of the areas we are working through at the moment is the transfer of contact information of individuals and organisations who are Affiliates of the JLA to NETSCC. We will be emailing all Affiliates shortly to explain the



process of transfer and when it will happen. This will be a process managed between the JLA and NETSCC, so there is nothing for individuals to do, unless your contact details have changed. If this is the case then we will be asking you to update your records with us. Whilst the data owner will continue to be the NIHR, NETSCC will become the new data processors and therefore we'll be sending you some information about how we'll store your data and what we'll use it for.

### JLA Website

From April 2013, we will be responsible for maintaining and updating the JLA website and as such, we are starting work on considering both the technicalities of this and also the branding of it. The JLA will be branded as working in partnership with the NIHR and whilst the content of the website won't be changed dramatically, we are considering the look and feel of it and aiming to enhance the navigation for users. We will also be including the JLA Guidebook as part of the main website.

### JLA Advisers

Our tender for bids to become JLA Advisers has now closed and we're now considering the applications. Hopefully we'll be able to confirm the outcome in the next newsletter!



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## Tackling the Twittersphere

By Katherine Cowan

It is hard not to have heard of Twitter these days. A micro blogging site, where individuals and organisations can share their thoughts, feelings, ideas and innovations using 140 characters or less, it documents the comings and goings of everyone from the Dalai Lama to the Daily Mail. The JLA has been tweeting for over a year now, and has amassed a band of over 800 followers. When I was tasked with responsibility of setting up our Twitter feed, I was initially sceptical: did we really want to know what members of the online community were having for their breakfast? I quickly revised my opinion. While breakfast detail-sharing does go on in some quarters, it is also a place for discovery and debate. Twitter has enabled the JLA to raise its profile globally, to promote the work of the Priority Setting Partnerships (PSPs) to new audiences, to encourage interest in patient and carer involvement in research, and to find out what people are saying, producing and publishing on the topic. During the process of setting up our Twitter feed I was given some really helpful advice from friends and colleagues, and have in turn passed those tips on to others who are composing their first tentative tweets. You've heard all about the JLA's top 10 priorities for research. Here are our top 10 tips for Tweeting:



Katherine Cowan

1. **Have something to say.** Before you get started, line up some things to tweet about, such as who you are, what you do, interesting links and so on. Then drip feed these into the Twittersphere, thus generating people's interest. My JLA colleagues also regularly send me topics to tweet about.
2. **Maintain your presence.** It's a good idea to tweet regularly, so people start to know you as a contributor and will look out for you. I find that people seem to respond and retweet (ie copy what I've tweeted to their followers) mostly during



working hours. If you're going away, you can upload some tweets on Tweet Deck ([www.tweetdeck.com](http://www.tweetdeck.com)), where you can set them to go out on a timer – thanks @EvidenceAid for alerting me to that.

3. **Follow and be followed.** I have found that the more people we've followed, the more will then follow us. As a first step, I tracked down the people and groups we already collaborated with, and then looked at who they were following – we pilfered shamelessly from the follow files of @profsandyoliver, @PPIsqueek, @cochranecollab, @officialNIHR and @sdenegri, among others.
4. **#Hashtag.** The hashtag is a useful way of flagging up your topic. So for a tweet about our Schizophrenia partnership, I used #schizophrenia, which drew it to the attention of anyone following that hashtag, even if they weren't following us. It's worth doing a search to see if a common abbreviation of your topic is being hashtagged before you invent your own.
5. **Retweet.** When you retweet what someone else has tweeted, it will appear in your followers' timelines, even if they don't follow the original tweeter. Retweeting not only allows you to share interesting and relevant information, but it also often results in your tweets being retweeted in return. When we were first retweeted by @BMJ\_latest to over 50,000 followers, it was an exciting moment.
6. **Set up searches.** I have a list of terms which I've saved in my search preferences (eg 'priority setting', 'James Lind', 'consumer involvement' and our PSPs' topics) and I regularly check them to see what people are saying about them, retweeting or replying to anything interesting.
7. **Be typographically economical.** 140 characters do not go far, so don't be shy about using shorthand. If you include the whole http:// address for a web link, it will be automatically shortened. In real life I would never replace 'for' with '4' or 'thanks' with 'thx', but on Twitter it's acceptable.
8. **Have conversations.** Getting into public discussions by clicking reply on a tweet you like is a useful way to raise your profile and connect with others. @EmmaMalcolmCEO first suggested this, and although I initially felt shy, a Twitter conversation with @JudithPotts resulted in her writing an article about the JLA for her Daily Telegraph blog.
9. **Follow Friday!** This is a very jolly event that happens at the end of your working week. Using the hashtag #FF you list any tweeters (always prefix their user name with the @ sign) which you would like to publicise as being worth following. These will often be retweeted by the people you mentioned, further increasing your profile among their followers. And it's a nice thing to do.
10. **Twitter time management.** A couple of colleagues, who shall remain nameless, have suggested that they can't tweet as it will take up too much time. Indeed, that Twitter will consume your entire day/life is a very real danger. It's therefore important to set aside specific tweeting times, and to routinely inspect the profiles of your favourite tweeters, rather than wade through everything on your timeline to find them. I'm now over the initial shock (and feelings of inadequacy) I felt when I first saw that a colleague had been tweeting in a professional capacity at 11pm. If you don't want it to take over, don't let it.

If you're new to Twitter, I hope this will help you. It doesn't take long to build your confidence, and to develop your own tricks and techniques for making the most of it. If you're already Tweeting, is there anything I've missed? What advice would you give to new Twitterers? Tweet me @LindAlliance using the hashtag #JLAtweet.

[www.twitter.com/LindAlliance](http://www.twitter.com/LindAlliance)



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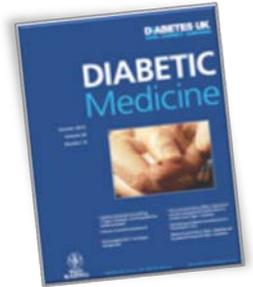
Chalmers, I., Essali, A., Rezk, E. and Crowe, S. (2012) 'Is academia meeting the needs of non-academic users of the results of research?', *The Lancet*, published online 8 October 2012

<http://download.thelancet.com/flatcontentassets/pdfs/palestine2012/palestine2012-31.pdf>.

Medical and public health researchers often assume that their work will be relevant to patients, health professionals, policy makers, the public, and other non-academic users of research. However, on the basis of the little available evidence, serious mismatches exist between what researchers do and what many non-academic users of research feel they need. Research agendas are determined by the priorities of research sponsors, academia, and academic researchers, and cannot be assumed to match the needs of non-academic users of research. The authors reviewed themes that emerged from the JLA PSPs for asthma, incontinence, vitiligo, eczema, stroke, prostate cancer, schizophrenia, aspects of balance, and type 1 diabetes. Emergent themes include emphasis on the need to assess long-term effects (wanted and unwanted) of treatments; safety and adverse effects of treatments; effects of complementary and non-prescribed treatments; and the effectiveness and safety of self-care. The authors suggest that researchers need to consider their responsibilities to take account of the needs of public and other users of research and ask themselves what they are doing to ensure that they are meeting these needs. Furthermore, non-academic users of research need to engage with the research community to encourage research that addresses their needs.

Gadsby R., Snow R., Daly A., Crowe S., Matyka K., Hall B. and Petrie J. (2012) *Setting research priorities for Type 1 diabetes*, 'Diabetic Medicine', October 2012, vol./is. 29/10(1321-1326), 0742-3071;1464-5491

Describes in detail the process and methods adopted by the Type 1 Diabetes PSP. Shown that it is possible using the JLA process to develop an agreed top 10 list of research priorities from health professionals, patients and carers.



European Science Foundation (2012) *Implementation of Medical Research in Clinical Practice*, Science Policy Briefing 45, September 2012

This guidance recommends involving patients and the public in making decisions about prioritisation, funding, planning, conduct and reporting of clinical comparative effectiveness research and evidence based medicine, citing the JLA as an organisation which can play a key role in this.



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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).



## CURRENT AFFILIATES

The JLA currently has 523 Affiliates, most of whom are listed on our website. The Affiliates programme is for organisations and individuals who identify strongly with the objectives of the JLA, and want to express support for, be involved in or simply be kept informed about the JLA's activities. It's quick, easy and free to become a JLA Affiliate. You'll receive this bi-monthly newsletter on email 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.

## 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.

## 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 2013.

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