



Affiliates Newsletter – January 2011

MESSAGE FROM THE CHAIR

Dear colleague,

Happy New Year!

I thought I would use this first letter of 2011 to remind everyone that James Lind Alliance is not about patient priorities for research but, about priorities shared by patients and clinicians.

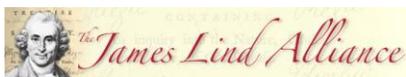
So often, the increasingly popular badge of 'PPI' (patient and public involvement) is applied liberally and it would be easy to understand if the general public saw the JLA as simply another group endeavouring to spread that (important) message.

In modern speak, our Unique Selling Proposition (you can tell I have not lost all of my banker parlance), which really sets us apart from the PPI agenda, is most definitely the *combined* voices and views of patients and clinicians. Whilst I hope I am not teaching egg-sucking, this distinction is so important for us at JLA. I just wanted use this opportunity to restate it.

Every good wish for 2011 and please do keep letting us have any views or suggestions that you think may help us to do our job better.

Thanks, as always, for your support,

Lester Firkins, Chair, James Lind Alliance



NEWS

JLA Eczema Priority Setting Partnership launched

Over the coming months, researchers from the Centre of Evidence Based Dermatology at the University of Nottingham (www.nottingham.ac.uk/dermatology) will be working with the JLA to establish a Priority Setting Partnership (PSP) of patients, carers, clinicians, patient support groups and charitable bodies, to establish what the most important treatment uncertainties are in the field of eczema. Once these have been identified, all of the treatment uncertainties will be uploaded onto the UK Database of Uncertainties about the Effects of Treatments (UK DUETs), where they can be freely viewed by research funding bodies and others.



This work is part of a larger project called SPRUSD looking at various skin diseases, including eczema, skin cancer, vitiligo and a rare ulcerative condition called pyoderma gangrenosum. This independent research is being supported through a Programme Grant funded by the National Institute for Health Research (www.nihr.ac.uk).

In early 2011, the PSP will be sending out a survey that will be available through the National Eczema Society's website (www.eczema.org). All submitted questions/uncertainties will be processed so that similar submissions are combined and checked to see if they are true uncertainties that require further research. The PSP will then be asking patients, carers and clinicians to collaborate to prioritise the questions, and to agree to a list of the top 10 most important treatment uncertainties in eczema. This list will then be used to develop trials (and other research) to address these uncertainties.

We will include further details of the survey in the next Newsletter, but in the meantime if you have any questions about the Eczema PSP, please contact Tessa Clarke at ukdctn@nottingham.ac.uk.



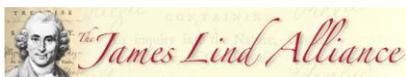
The University of
Nottingham

Funding disclaimer:

This article presents independent research commissioned by the National Institute for Health Research (NIHR). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health

Patient and Public Involvement in the Clinical Research Networks: The Way Forward

The Department of Health has highlighted the need for greater coherence, collaboration and coordination for the organisation of patient/user involvement (PPI) and in the way patients, carers and the public are involved in the activities of the National Institute for Health Research (NIHR) Clinical Research Networks. *The Way Forward* report, by Derek Stewart, has made four core recommendations: identify and target activity within a commonly agreed framework; develop better cross-network and cross-NIHR collaboration; formalise evidence gathering and dissemination; and integrate learning and development opportunities. These will be developed and embedded in a plan for PPI across the Clinical Research Networks. This plan will then be incorporated into a Business Case submitted to the Department of Health by March 2011. If funding is approved, it will enable delivery of a Clinical Research Network PPI



Programme through to 2015, which will be integrated with individual Network Business Plans. An Implementation Steering Group has been established to promote the development of the business case, and the JLA has recently been invited to sit on this group. The group will ensure the recommendations of *The Way Forward* report are translated into a clear business plan, with associated objectives for PPI across the Networks. These will be aligned to and reflect the High Level Objectives of the NIHR Clinical Research Network. It will also oversee and guide the development of the Business Case to be submitted to the Department of Health. The work of the steering group will be completed by the end of March 2011. We will keep you updated on the outcomes of this important project. For further details, please contact Project Coordinator, Roger Steel: roger.steel@nihr.ac.uk.

A Route Map for Patient and Public Involvement

The Association of Medical Research Charities (AMRC) and TwoCan Associates have developed an interactive route map for health research charities and other organisations commissioning research and wishing to involve service users in their work. As Sophie Petit-Zeman, head of external relations at AMRC explains, "It looks like a very simplified underground map, with three 'main lines' - one on user involvement in research management, one on the infrastructure to support user involvement, and the third on promoting and supporting it. Within those main lines, questions include 'why involve service users', and there are 'stations' about evaluation and methods of recruitment." The map can be found at www.amrc.org.uk/our-members_natural-ground:-patient-and-public-involvement-project_ppi:-resources.



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

Sally Crowe, Chair of the JLA's Monitoring & Implementation Group, and lead for the Type 1 Diabetes PSP reports: "The initial work on the survey data is complete. It is our biggest survey response yet, and has resulted in 350 verified treatment uncertainties. Of these, 250 are single unique uncertainties and the rest are indicative. The latter term means that where uncertainties are essentially the same but expressed in a slightly different way, they are combined with slight rewording to reflect the range of survey submissions. This presents this PSP steering group with a challenge – we know that sending out a list of 350 treatment uncertainties for interim voting is too much! The steering group will meet in early 2011 to reduce the



Sally Crowe



list of 350 to something more manageable for a priority setting exercise in summer 2011. All the uncertainties will be published on the UK DUETs database during 2011. Thank you to all of the organisations and individuals who have contacted the JLA expressing their interest in priority setting type 1 diabetes treatment uncertainties. We will be in contact soon with more news.”

If you or your organisation haven't registered your interest in being involved please contact Sally Crowe on sally@crowe-associates.co.uk or ring 01844 216929.

Schizophrenia

The Schizophrenia PSP held its final priority setting workshop on Monday 10th January, and was attended by service users, carers, charity representatives and clinicians, including psychiatrists, psychologists and social workers. A series of small group and plenary discussions, facilitated by the JLA, resulted in agreement on a list of the top 10 treatment uncertainties for schizophrenia. “The workshop was a really excellent forum to bring together clinicians, service users and carers to look at research priorities – and debate these within a framework that we knew had to reach a consensus outcome,” said Vanessa Pinfold, Director of Research at the mental health charity Rethink. Keith Lloyd, Professor of Psychological Medicine at Swansea University, who led the original exercise to identify the treatment uncertainties, described the workshop as “The most interesting and stimulating experience I have ever had thinking about research priorities”. The Steering Group is now working on a



Participants consider and begin to agree their priorities

dissemination strategy for the top 10, to bring it to the attention of research funders and to have maximum impact within the schizophrenia community. This work is being coordinated by Jo White at Swansea University. We will keep you updated on the next steps as they occur. The JLA would particularly like to thank Jo White for all the work she did to ensure the workshop ran smoothly, and Thomas Kabir at the Mental Health Research Network for making all the arrangements for hosting the meeting. For further details please contact Jo White (j.white@swansea.ac.uk).

Life after stroke in Scotland

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

“From the 30th November to the 3rd December we were busy attending the UK Stroke Forum Annual Conference where we had successfully secured a stand at the ‘Ideas Fair.’ Our aim was to gather research uncertainties relating to life after stroke and raise awareness of our project with an interactive-styled stand. We were very encouraged by the response to the Life after Stroke in Scotland project and collected research uncertainties from delegates, some of whom were stroke survivors and some of whom were health professionals, but all with interesting and varied stories and viewpoints. We have also distributed



Bridget St George and Alex Pollock manning the Life after stroke in Scotland stand, at the UK Stroke Forum annual conference.



leaflets and response forms to stroke groups across Scotland and have been very pleased with the response to this, with lists of uncertainties being sent back by post from groups such as the Highland patients and carers MCN Group.

“So far we have gathered almost 200 uncertainties about Life after stroke in Scotland and our PSP Steering Group members have visited 10 different Stroke Groups with more visits booked in for the coming weeks. We will continue with our ‘road show,’ covering as many areas of Scotland, over the next few weeks. We are also in the process of contacting relevant professional organisations by email. We plan to keep gathering uncertainties until the end of February.”

For further details, or to get involved, please contact Alex Pollock (Alex.Pollock@gcu.ac.uk). Information sheets, response forms and presentations with narration can be found at www.askdoris.org/D_JLA.asp.



Pressure ulcers



The initial awareness meeting for the Pressure Ulcer Priority Setting Partnership had to be postponed due to adverse weather conditions. It has been rearranged for Tuesday 22nd March in York. Practitioners involved in pressure ulcer treatment and care, and patients and carers who have experience of living with pressure sores, would be welcome to join us at this meeting. It will be a combination of small group discussions about living with and treating pressure sores and presentations and discussion about gathering treatment uncertainties and prioritising them. Lunch and refreshments will be provided, and travel (and overnight stay where appropriate) costs will be met. For further information, please contact Sally Crowe (sally@crowe-associates.co.uk) or Dr. Mary Madden (mm538@york.ac.uk). Or go to www.ilapressureulcerpartnership.co.uk.

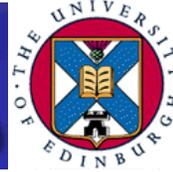
Ear, nose and throat – aspects of balance

The bulk of the treatment uncertainties have now been harvested and the team is engaged in refining and formatting the list. This will then go out to interested parties for the first stage of priority setting voting. If you would like any further information, contact Jo White jo@entuk.org.

Prostate cancer

With the final priority setting workshop behind us, efforts are now focussed on drafting publications so that the outcomes can have maximum impact. Hopefully, by the time of the next newsletter these should be near completion and we can bring you an update.





A starting point to identify areas for further research around recovery and quality of life among intensive care unit (ICU) survivors – by Claire Kydonaki

A very successful event took place in October 2010 in Edinburgh, the aim of which was to bring critical care clinicians, former patients and researchers together to begin to identify those aspects of patient experience after intensive care that need to be addressed by further research. The event was funded by the Scottish Intensive Care Society and was run jointly by the Edinburgh Critical Care Research Group, the University of Edinburgh and the JLA. Participants comprised of former intensive care patients, their family members, hospital and community-based staff (including doctors, nurses, physiotherapists etc) from across Scotland, and researchers from the University of Edinburgh.

The event took place at the Royal Infirmary in Edinburgh. The day began with powerful and highly compelling talks by two former intensive care patients and was followed by short presentations from leading researchers in the field. In the subsequent 'break out' sessions in small groups, former ICU patients and their family members were invited to talk about their past experiences of recovery with clinicians and researchers. An intended outcome of this interactive session was the identification of the 'top ten' most important areas of patient care for future research. These included experiences of Intensive Care, experiences of ward-based rehabilitation, and experiences of hospital discharge and recovery at home.



On reflection, we felt that the research areas identified were best represented in terms of their relevance within and across the critical illness journey, and that transition of care was a central theme (see Table 1).

Areas for research across the critical illness journey		
ICU	Wards	Home
1. Managing pain and comfort 2. Sedation and neuropsychological sequelae (dreams, hallucinations and cognitive impairment) 3. Sleep 4. Improving communication for/with patients 5. Improving information and support (including legal, financial and social aspects) for families 6. Improve understanding of the ICU environment/routine and its effects upon the patient	1. Improving discharge planning and communication between ICU/wards/ community 2. Developing models of step-down/care pathways 3. Improving psychological support for patients 4. Sleep 5. Improving information and support for patients and families 6. Improving nutrition 7. Timing and intensity of physiotherapy to avoid muscle wasting and fatigue 8. Improving staff understanding of the patient's experience	1. Improving physical recovery with community rehabilitation 2. Psychological support for patients (including support groups) 3. Understanding the effects upon family members (physical, psychological, financial) 4. Improving information and support for families 5. Improving understanding among GPs (information, education) 6. Improving access to community services 7. Understanding the longer-term effects of critical illness

Table 1. Identified areas of research during the critical care journey.



Within that theme, we identified patient and service-related issues (see Table 2).

Patient-related issues	Service-related issues
Improving physical recovery	Improving staff (ICU, ward and GPs) understanding through information and education
Improving psychological support	Developing models/pathways of care for a "joined up" service
Communication, information and support for patients and families	Improving access to community resources

Table 2. Main patient and service-related issues identified.

Patient participants were 'glad to have had the chance to express their views', whereas clinicians found the day was 'a real eye-opener' in terms of 'the issues that patients and their families face'. We hope that this event was only the beginning for the improvement of the quality of life for ICU survivors and their families. Research questions, emerging from the outcomes of this event, will initiate further studies to inform constructive and patient-centred policies in service delivery for former critical care patients and their families.

For further information, please contact Claire Kydonaki (k_kidonaki@hotmail.com) or Pam Ramsay (pam.ramsay@luht.scot.nhs.uk), ECCRG and University of Edinburgh.

.....

FORTHCOMING EVENTS

COMET: Core Outcome Measures in Effectiveness Trials



Following the launch of the COMET Initiative in Liverpool last year, the second COMET meeting will take place in Bristol on 11-12th July 2011. The meeting is part of a programme of work focussing on outcomes to be measured in clinical trials and will bring together trialists, health professionals, patients and public representatives, journal editors, policymakers, regulators, research funders, Cochrane editors and authors, and methodologists interested in the development and application of "core outcome sets" in many different areas of healthcare practice and research.

More details can be found on the website www.cometmeeting2011.org. Registration is free of charge and is now open via the website. Please be advised that places are limited and early registration is encouraged. If you would like to submit an abstract for poster presentation at the meeting, this can also be done via the website. Further information about COMET can be found at the website www.liv.ac.uk/nwhtml/comet/comet.htm along with podcasts from the launch meeting in Liverpool.

16th Annual Meeting of UK and Ireland Contributors to The Cochrane Collaboration

The JLA will be participating in the 16th Annual Meeting of UK and Ireland Contributors to The Cochrane Collaboration, in Belfast. The meeting provides an opportunity for UK and Ireland-based members actively involved with The Cochrane Collaboration to get together to learn, debate and network. Sally Crowe will be working with systematic reviewers and consumers involved in Cochrane Reviews, sharing experiences and ideas for prioritising



review topics and exploring how a wide range of stakeholders can be involved. For more information go to: <https://asp.artegis.com/lp/BelfastRegistration/cochrane?1=1>

If you would like the JLA to participate in your event, let us know. We can then promote it in the Newsletter.

IN PRINT

Stewart, R. J., Caird, J., Oliver, K. and Oliver, S., Patients' and clinicians' research priorities. **Health Expectations**. Article first published online: 22 DEC 2010 | DOI: 10.1111/j.1369-7625.2010.00648.x.

Abstract

Background If research addresses the questions of relevance to patients and clinicians, decision-makers will be better equipped to design and deliver health services which meet their needs. To this end, a number of initiatives have engaged patients and clinicians in setting research agendas. This paper aimed to scope the research literature addressing such efforts.

Methods A systematic search strategy combined electronic searches of bibliographic databases with handsearching and contacting key authors. Two researchers, initially working independently, described the relevant reports. The study was funded by the JLA.

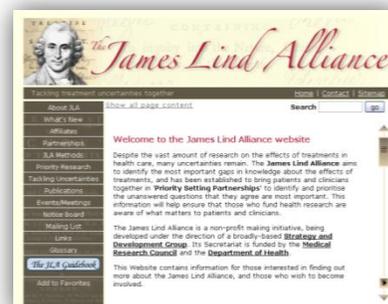
Findings Over 250 studies addressed patients' or clinicians' priorities for research and outcomes for assessment. This literature described different routes for patients and clinicians to contribute to research agendas. Two-thirds of the studies addressing patients' or clinicians' research questions were applicable across health care, with the remainder focussed on specific health conditions. The 27 formal studies of patient involvement revealed a literature that has grown in the last decade. Although only nine studies engaged patients and clinicians in identifying research questions together, they show that methods have advanced over time, with all of them engaging participants directly and repeatedly in facilitated debate and most employing formal decision-making procedures.

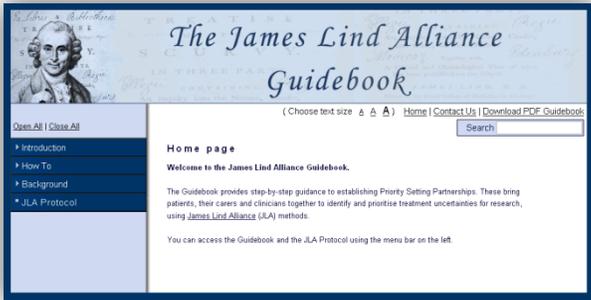
Conclusion A sizeable literature is available to inform priorities for research and the methods for setting research agendas with patients and clinicians. We recommend that research funders and researchers draw on this literature to provide relevant research for health service decision-makers.



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 287 Affiliates, most of which are listed on our website. One of our Affiliates is the Cleft Lip and Palate Association (CLAPA), a registered charity in the UK which was set up 31 years ago to support people born with a cleft lip and/or palate and their families. "Depending on the nature and severity of the cleft people face a treatment pathway of 20 years from birth and we are also seeing adults return for treatment later in life," says Rosanna Preston, CLAPA's Chief Executive. "A cleft can affect not only appearance but also feeding and breathing in infants, and speech and hearing later in life, and may result in multiple operations plus orthodontic treatment and speech and language therapy."



Robert, before and after surgery

CLAPA launched a free membership scheme in 2009 and now has over 6,000 members. CLAPA is the representative body for people affected by cleft lip and/or palate and advocates for maintained or improved NHS services. CLAPA's prime services are: the provision of information through leaflets



and the website; support for new parents including specialist feeding equipment and face to face contact with other parents who have been through the same situation; activities and information for children and young people growing up with a cleft; and support for adults looking for further treatment. It provides its services from a small national office and network of volunteer run branches and is supporting its members to become more involved in evaluating services provided by the NHS and in research.

“The JLA is of great interest to CLAPA because it gives equal weight to the patient and medical perspectives,” says Rosanna. “We are just embarking on a PSP to identify the key unanswered questions in cleft lip and palate research. There is a great deal of exciting research activity in this field and we welcome the opportunity to ensure that the research addresses the questions important to people affected by cleft lip and palate. If people would like to know more about the PSP or the work of CLAPA in general they are welcome to contact me on rosanna.preston@clapa.com.”

For further information about CLAPA’s work, please visit www.clapa.com.

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 March 2011.

Katherine Cowan
James Lind Alliance
Summertown Pavilion
Middle Way
Oxford OX2 7LG

katherine@katherinecowan.net

www.lindalliance.org

