

## Minutes of the 22nd Meeting of the James Lind Alliance Strategy and Development Group, Royal Society of Medicine, London, 29 Nov 2011.

### Participants:

Miss Lizzie Amis	Project Manager, Patient and Public Involvement Programme, NICE
Ms Patricia Atkinson	Administrator, James Lind Alliance Secretariat
Dr Brian Buckley- <i>Apologies</i>	Primary Care Researcher, Cochrane Fellow and Chairman of Bladder and Bowel Foundation
Sir Iain Chalmers	Editor, James Lind Library
Dr Mabel Chew- <i>Apologies</i>	Associate editor, BMJ
Ms Katherine Cowan	Independent Consultant
Mrs Sally Crowe	Director, Crowe Associates
Mr Simon Denegri	Chair, INVOLVE
Mr Lester Firkins	Business consultant, for NIHR
Mr Tom Foulkes	Medical Research Council
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Prof Stephen Holgate- <i>Apologies</i>	Physician, Southampton General Hospital
Dr Susan Kerrison- <i>Apologies</i>	Assistant Director Research and Development University College London Hospitals Trust
Ms Emma Malcolm	Chief Executive, Prostate Action
Prof Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Sir Nick Partridge	Director, Terence Higgins Trust
Dr Kay Pattison	NIHR National Programme Manager, Research and Development, Department of Health
Dr Sophie Petit-Zeman	Adviser, Public Involvement & Engagement, Association of Medical Research Charities
Dr John Scadding- <i>Apologies</i>	Emeritus Dean, Royal Society of Medicine
Mr Derek Stewart OBE	Director, Patient & Public Involvement, NIHR Clinical Research Network Coordinating Centre (NIHR CRN CC)
Dr David Tovey	Editor in Chief, The Cochrane Library
Ms Pamela Young	Specialist Programme Manager, NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)
<b>Invited Guests:</b>	
Mark Fenton	Project Manager, UK DUETs, NICE (NHS Evidence)
Dave O'Carroll	Information and Communications Manager (Research & Innovation), Learning & Development Institute, Royal College of Nursing
Professor Ruairidh Milne ( <i>left the meeting at the end of item 5</i> )	Director of External Relations, NETSCC
Alexia Tonnel	Interim Programme Director: Evidence Resources, NICE (NHS Evidence)

### 1. Welcome from the chair

LF welcomed everyone to the meeting of the James Lind Alliance (JLA) Strategy and Development Group (SDG).

### 2. Minutes of the 5 MAY 2011

The minutes of the last meeting were accepted.

### Matters arising

LF said that IC had attended the Balance Disorders Priority Setting Partnership's (PSP) final workshop as an observer. LF encourages anyone who has not yet seen a PSP meeting in action to attend, as it helps to put many of the issues and challenges in context. PA will send a list of upcoming PSP final meetings to SDG members for those who wish to observe a prioritisation meeting.

### Action: PA

LF said that he and SO were in the final stages of delivering the objective set by the MRC. This is to investigate whether JLA methods can help the MRC improve the ways in which it includes patients and non-research clinicians in its research priority setting.

SPZ said that the BMJ has rejected the idea of publishing the results of the JLA PSP's in their uncertainties column, but that the journal Nature is interested. SPZ's article 'Stroke survivors have their say on research priorities' has been published in The Guardian. <http://www.guardian.co.uk/society/2011/nov/29/stroke-survivors-highlight-research-priorities>

SC & SPZ, with input from the other JLA Monitoring and Implementation Group (MIG) members, are working on the review of PSP priorities to assess what impact they have had. EM will send SC an update of the Prostate Cancer PSP work.

**Action: EM**

### 3. **JLA – The early years**

SC gave a retrospective presentation of the JLA, charting the achievements and challenges. Key points below:

#### **Key achievements**

- Concept of treatment uncertainties and shared prioritisation to inform future research agenda
- Partnership model for gathering, publishing and prioritising treatment uncertainties, with underpinning principals and values
- Focus for priority setting methods and results
- Replicating the model and generating publications
- Going mainstream!

#### **Priority Setting Partnerships**

- PSPs then – JLA, UK DUETS, Professional Organisations and Patient Charities
- PSPs now – JLA, UK DUETs, Professional Groups, Patient/Carer Groups, Medical Research Charities, Cochrane Review Groups and Clinical Research Networks
- Working in a democratic, open and evidence-based way
- PSP's completed to prioritisation – Asthma, ENT Aspects of Balance, Prostate Cancer, Schizophrenia, Stroke, Type 1 Diabetes, Urinary Incontinence and Vitiligo.
- Current PSP's – Cleft Lip and/or Palate, Eczema, Head and Neck Cancer, Lyme Disease, Pressure Ulcers, Pre-term Birth, and Tinnitus.

#### **Are there priority themes emerging across health problems?**

- Long term effects of treatments
- Safety and adverse effects of treatments
- Use of non-prescribed treatments
- Professional training and education (for early diagnosis and treatment and to harmonise clinical behaviour), especially GPs
- Self care – effectiveness and safety

Is this the difference that a shared debate makes?

#### **Revisiting Asthma UK and Cochrane Airways Group (CAG)**

- CAG and JLA are now working with Asthma UK on priorities for their research strategy and next round of funding – workshop on Dec 6th 2011
- "To create indicative domains by grouping the ~250 questions generated by the, JLA initiative in 2007." How do these relate to CAG's current review portfolio?

#### **Challenges so far.....**

- Clinician engagement remains patchy in PSPs
- The work of turning survey responses into PICO questions – a dark art!
- The balance of PSPs owning what they do – and needing support from JLA and UK DUETs
- Getting top tens into the best possible state to appeal to research funders, commissioners and review groups
- Balance of publicity vs. operational work

### **And still to be achieved.....**

- Still much more work to do to convince senior people in research commissioning and funding that we have a viable method and useful outputs – ‘Building on Success’ event
- Difficult to assess and evaluate progress in this
- Being perceived as only interested in the patient agenda (*but that is changing*)
- Keeping track of all priorities and what happens to them

*Copy of presentation available from PA*

## **4. The Future**

LF gave a presentation, outlining plans for the future, key points below:

### **Thinking and planning**

- 2010-2013 Objectives included an imperative that JLA methods needed to become “mainstreamed”
- Tentative discussions at SDG and also with NIHR as main funders
- View taken that NETSCC could be a sensible home to capture benefits of NIHR spend so far, and also provide a stable base for the future

### **Discussions**

- August 2010 – off-line discussions with Kay Pattison, Lynn Kerridge, Ruairidh Milne and Iain Chalmers
- September 2010 NETSCC Board agreed in principle to transfer of JLA – subject to detailed planning.
- February 2011- Transition working group formed; Kay (Chair), Lynn, Ruairidh (NETSCC), and Sally, Lester (JLA)
- Several meetings – and now v5 Business Plan, Oct 2011

### **The Business Model**

- Considering general “Direction of travel”
  - How can we make sure we address the NIHR priority areas?
  - How can we also support “self funded” PSPs that approach us?
  - How should supervision and governance work?
  - Need to define current and future scope of PSPs

### **The Transition Period**

- Close working together starts April 2012
- Detailed processes to be defined
  - Describe
  - Test
  - Sign-off
- Staffing requirements to be defined
  - Job descriptions written
  - Agree competencies
  - Advertise
  - Recruit
  - Train and work in parallel
- All New PSPs move towards new model
- Existing PSPs to be managed to completion, or be aware of model change
- Website and Guidebook amended to reflect new model
- Procedure “manuals” to be agreed

RM gave a brief explanation of how NETSCC and NIHR work, and said that working with JLA is important and central to NETSCC’s mission. RM said he is also working on the avoidable waste in research project with IC and Paul Glasziou. He said that the JLA is one way of looking at research questions that involve different stakeholders.

RM said that it would be a challenge to work out a model which incorporates the best of the

JLA, as it moves from a free standing environment to a mainstream and more formal organisation.

RM outlined the highlights of the business plan. He said that the Department of Health is intending to fund a hub/secretariat, at NETSCC – tasks to include the establishment of an advisory group, maintenance of the JLA guidebook/website/twitter/newsletter and the affiliates database – as well as expert advisers (funding described in the next para).

He said the Department of Health is also considering funding PSPs, circa £20k per PSP, in areas that are important to NIHR, this funding will go further if others involved provide additional funding. He said that it is important to ensure the key elements of the PSP as run by JLA and UK DUETs are maintained, involving comparable numbers of patients, carers and clinicians. Expert advisers will be funded through this funding for PSPs.

## **5. Open Discussion – Key points raised**

EM asked how the NIHR would select new PSPs and NP asked what the priority areas would be. KP said this was still being thought through but that it was important that NIHR funding supported NIHR priorities.

JH said it would be important not to lose the expertise of the JLA consultants. IC suggested that JLA Facilitator would be a better title than Expert Advisor.

SO said that leading up to the transfer some form of succession planning would be needed. LF and SC agreed that this would be a priority for 2012

Will NETSCC be setting priorities across conditions where there are themes in priorities across conditions?

How the JLA is badged was considered to be important. Is it part of the NETSCC programme? Is it hosted by NETSCC as a catalyst for change? Consideration needs to be given to how the JLA is branded and how this might impact on the perceptions and willingness of those who might get involved.

How can the process be relatively simple/short within a complex organisation?

LF asked members of the SDG to email any further comments and suggestions that they might have.

## **6 Working with UK DUETs**

IC raised the issue of the scope of uncertainties coming out of the JLA PSPs, and submitted to UK DUETs. Some of the uncertainties have been about tests, aetiology and prognosis, not treatments, and that there was a need for a strategic and thorough discussion on these inconsistencies. The strategic implications have to be confronted before transfer to NETSCC. After further discussion it was decided that the JLA MIG would look into this in more detail and discuss with IC. It will also be discussed at the UK DUETs SG meeting in January.

MF gave an overview of the UK DUETs work he is involved with in NHS Evidence. He said that Evidence Updates are carried out to ensure new information is available before/while clinical guidance is updated. He said that anyone finding uncertainties additional to those already in UK DUETs should let him know so that they can be entered into the database, if eligible. He is working with other colleagues to get uncertainties from other areas. He said the guidelines are not just about treatments and included NICE and other research recommendations.

AT talked about existing development, and said that they were working on the ability to import content into UK DUETs, and an uncertainties feed from the Cochrane Library in bulk. She said that a new Programme Manager had been engaged as further support for MF.

IC asked about the ability to easily identify JLA and other priorities in NHS Evidence. MF said

that this was a work in progress and he is working on a short term fix to make this aspect more user friendly. MF said it is a current objective to be able to identify top priorities in general, and their sources.

AT said NHS Evidence is working on a new feature which will distinguish between uncertainties (derived from physicians/patients) and research recommendations.

IC said that, as far as he is aware, NHS Evidence is the only bibliographic source in the world that enables searchers to retrieve uncertainties.

MF said that his support to the PSPs will continue at its current level unless changes are required by NETSCC.

## 7 **Where are we now?**

KC gave an overview of where the JLA is now. She said that the website had been updated and would be further updated with comments/suggestions received from the feedback received. IC said that the British Library is archiving the JLA website.

KC said that the JLA online guidebook is updated regularly, and is a useful place to add examples of good practice.

She said that the number of JLA Affiliates has grown, and that the Affiliate programme gives the JLA the benefit of access to a wider range of individuals/organisations, and to partnership work. The benefits to Affiliates are the JLA newsletter, and access to a network/community of interest. KC will suggest to NETSCC that more use be made of the Affiliates, for example, in networking events and development opportunities.

KC said the JLA Newsletter is receiving very good feedback. It regularly features news from the PSPs as well as practical examples of their work and opportunities for partners to share good practice and learning. Steps have been taken to ensure balanced input from patient and clinician perspectives.

The JLA now has a Twitter account <http://twitter.com/LindAlliance>, and currently has over 200 followers. KC uses the account to promote the JLA, to encourage debate around the concept of patient/clinician involvement in research priority setting and to publicise the work of the PSPs, including their surveys and published papers.

What next? The JLA team will consolidate what they are doing now and start to work in detail on the migration process..

## 8. **Summary of day**

LF thanked everyone for attending and for the contributions made.

### **Future meetings:**

28<sup>th</sup> June and 7<sup>th</sup> November 2012