

## Minutes of the 11th Meeting of the Strategy and Development Group of the James Lind Alliance, Royal Society of Medicine, 14 January 2008

### Participants:

Ms Patricia Atkinson	Administrator, James Lind Alliance Secretariat
Sir Iain Chalmers	Editor, James Lind Library
Mrs Sally Crowe	Director, Crowe Associates
Mr Lester Firkins (Chair)	Business consultant, Medical Research Council
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Dr Susan Kerrison	Assistant Director Research and Development University College London Hospitals Trust
Dr Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Mr Nick Partridge	Chair, INVOLVE
Dr Sophie Petit-Zeman	Head of External Relations, Association of Medical Research Charities
Dr John Scadding	Dean, Royal Society of Medicine
Dr Chris Watkins	Board Programme Manager, Medical Research Council
Ms Pamela Young	Senior Programme Manager, National Coordinating Centre for Health Technology Assessment
Ms Philippa Yeeles	Programme Manager, UK Clinical Research Collaboration

### Invited Guests:

Ms Bec Hanley	TwoCan Associates
Dr Kristina Staley	TwoCan Associates

### Apologies:

Prof Glyn Elwyn	Chair, Primary Care, Cardiff University
Prof Stephen Holgate	Physician, Southampton General Hospital
Dr Marianne Miles	Patient/Public Liaison Lead, UK Clinical Research Network
Dr Peter Sneddon	Head of Research Programmes, Department of Health
Dr David Tovey	Editor, <i>Clinical Evidence</i> , <i>BMJ</i>
Dr Mark Welfare	Gastroenterologist/senior Lecturer Northumbria Healthcare NHS Trust

### 1. Welcome from the chair

LF welcomed members to the 11th meeting of the James Lind Alliance (JLA) Strategy and Development Group (SDG). SC said that Mark Welfare has stepped down due to other commitments. Mark will continue to offer his support. As well as Mark, Marcia Kelson and Charles Warlow also stood down in 2007. SC will write and thank them for their valuable input.

#### Action: SC

It was agreed that representation from NICE should continue to be sought; this will be followed up by LF and SC. It was also agreed that Working Partnerships representatives should attend the SDG meetings, as long as the SDG doesn't get too big/unmanageable. LF and SC to pursue further and update..

#### Action: LF & SC

### 2. Minutes of 27 September 2007

The minutes of the last meeting were accepted, with a minor amendment in Matters Arising.

#### Matters arising:

Item 5, Objective 1. Item updated with information from PY.

### 3. Research Priority Setting

Kristina Staley gave a progress report of the project 'A description of research priority setting (and the presence of patient and public involvement in priority setting), amongst the main clinical research funders in England'. All details are in the papers submitted to the SDG. The following were some of the issues raised by TwoCan Associates:

- Priorities for research differ between clinicians and patients, For example, in multiple sclerosis, patients identify fatigue as important, but researchers are not studying this
- Hard to evaluate the influence of research outcomes defined by patients and the public compared with those defined by clinicians/decision makers in funding organisations
- Evaluation of treatment accounts for only 8% of total public and charitable funding of biomedical research
- Funding operates in two different 'modes': 'responsive' and 'commissioned' There was discussion about whether different approaches for priority setting and PPI were needed in these different modes.
- Active involvement of carers was difficult in the examples examined
- Without much explicit priority setting found so far, peer review seems to be the way that most research either secures funding or not
- Despite a lack of evidence to support peer review, it is the agreed current 'best option' and used by most funders
- PPI in peer review is patchy

The following were some of the issues/ideas raised by the SDG:

- NP suggested that the second phase of the research should include major funders.
- CW said clarity was needed around the evaluation of the outcomes of the JLA's work. The robustness of JLA's priority-setting process would be a more important 'deliverable' than the actual priorities identified by the process.
- IC suggested that the next stage of TwoCan Associates' analysis should concentrate on stratifying the two main groups of funders into 'mainly commissioning' or 'mainly responsive', and collected information, if possible, on the proportion of total budgets used to these alternative modes of funding
- SO asked whether and how organisations separate discussions about funding and mechanisms to decide this and the topics themselves?
- SPZ said there is a need to clarify what peer review is, and what role it plays.
- How do organisations want priorities presented?

The SDG agreed the next steps as outlined in the submitted paper, and were asked to send any relevant information they have direct to TwoCan Associates. SC will discuss the issues raised with Kristina and Bec, and submit a short paper (to include amendments/additions to their contract if necessary) for review by the MIG. SC will feedback to the SDG.

**Action: SC**

#### 4. **Business Planning 2008-2010**

SC gave an overview of the JLA business planning meeting on 17 Dec 2007, and highlighted the following points arising:

- Strong endorsement to continue Working Partnerships
  - speed up
  - more efficient
- Communication and forcefulness of the key messages in JLA. How to engage more opinion formers and influential people in research.
- Evaluation of JLA so far. Has it had an impact?
- Demonstrate our 'product' to funders and show its potential to improve research for patient benefit.

The following are some of the suggestions for delivering on JLA objectives:

- CW said that it is important that a robust and defensible methodology is produced for prioritising harvested uncertainties This is where the gaps are and this is what the JLA can offer the research community.
- IC said that the most relevant funding bodies are those that have a large commissioning element, especially the NHS HTA Programme. 'Responsive' funders may not be as interested in JLA priorities into which they have had no input.
- PY said the JLA package should be presented to prospective participants as a way to make their job easier and assist in the production of better research projects.

- NP suggested a need for a better model and how this is presented. He reminded the group of the aspiration we had for the JLA. He also questioned how long the JLA could keep its own momentum. Should this be evaluated? If the JLA produces, pilots, evaluates and reports its 'model', is this as much as it can do? This could be the natural end point of the endeavour, and provide a time-limited objective to work towards.
- JH said that getting the message out to patients that organisations do not always prioritise openly, and that this needs to be done through articles in patient journals.
- SPZ asked how the JLA's impact beyond the model and agreed priorities could be assessed? There needs to be some sort of measure that WPs improve quality of life. How do we know the product is the right one?
- JS said the JLA needs to show that the shared priorities of patients and clinicians in research about treatments are different (now and in the short-term); influence the research that gets done (in the medium term); and that this leads to better health (in the long term).

LF agreed to draft objectives for 2008 – 2009 based on these discussions, and distribute for comment.

**Action: LF**

## 5. 2008 Symposia Programme

### ***Transparency of funding in clinical research***

SC gave an overview of existing codes of conduct and outlined rough ideas for the seminar. SPZ suggested that a better title for this seminar would be "*Would your drug company consider funding the research outcomes of a JLA WP, with no strings attached if not, why not and why we feel uncomfortable about asking you?*". (but not as long!) As this is a difficult subject to pin down SPZ, NP and JH will discuss and formulate a draft plan for the meeting for further discussion.

**Action: SPZ, NP & JH**

### ***Patient-Reported Outcomes v Patient-Important Outcomes***

PROMs seminar has been re-scheduled for November 2008. Speakers and venues are being lined up.

## 6. Working Partnerships update

***Asthma*** – SC had a very good meeting with the Asthma WP on the 6 Dec at the BTS 2007 winter meeting, and gave a brief overview of the positive outcomes.

***Incontinence*** – A meeting of all the interested parties has been scheduled for 18 March to discuss progress, and issues raised on harvesting uncertainties.

Due to lack of time further updates on the Working Partnerships will be sent by email.

**Action: SC & LF**

## 7. DUETs – Progress towards DUETs modules

IC gave a brief report on progress with DUETs. In addition to Wales' existing involvement (through WORD's support of work on schizophrenia and epilepsy modules), Scotland is now involved as a result of a proposal by Gordon Lowe, chair of the Scottish Intercollegiate Guidelines Network (SIGN). A DUETs module on heart failure will be prepared by SIGN jointly with the NLH Specialist Library for Cardiovascular Disease. Maxine Whitton will lead the preparation of a DUETs module on Vitiligo as one of the outputs of the updating of her Cochrane review. On 13 May, IC will be speaking about DUETs at the stakeholders meeting of the NLH Specialist Library on Diabetes. Next phase of the work, after preliminary discussions with Asthma UK and the British Thoracic Society, will be to find out from funders which standard reports they would like to see produced by DUETs. A meeting is envisaged in June/July.

## 8. Update on Bibliography

SO gave a review of the work done so far to extend and assess the bibliography in preparation for a systematic review. SO asked the SDG to pass on to her any related reports or pieces of work that would be relevant and names of people she should contact.

SO would also like to know if there are any questions arising from the proposal paper. SO to write to Mark Fenton to ask him to keep her up-to-date of any DUETs/NLH changes that relate to the work she is doing.

**Action: SO**

**9. AOB**

SPZ reported, for information, a meeting between Simon Denegri (SD, AMRC Chief Exec) and Arthritis Research Campaign (arc) – a JLA affiliate (with whom IC has a meeting on 8 February). Many strands were relevant to the JLA, significantly:

- PPI: arc are in the process of putting in place more formal lay involvement for their response-mode funding activities from 1st Jan;
- Discussions with NICE on the 'Access to Medicines' issue which included deliberation on how arc and other research partners might modify the appraisal process by identifying the issues that need to be addressed.
- arc may conduct a large comparative study of all treatments in their field in order to use data about how a treatment fits into the overall landscape as part of recent and ongoing appraisals.
- Some positive progress with UKCRN was also reported: arc has taken a very proactive approach to the development of the Topic Network in their area and are pretty much leading its development, though they still feel it is too early to say whether the UKCRN model and infrastructure for fostering clinical studies and trials works.
- They are planning to bring together all the Network Research Directors together in early 2008 to identify issues with bureaucracy and process that they will then take to DH.

John Scadding reported that Iain Chalmers had named a chair in the new Max Rayne Auditorium, recently opened at the RSM. Iain proposed that the inscription on the donors board outside the lecture theatre should read:

***'In memory of Dr James Lind  
The James Lind Alliance'***

Iain was warmly thanked for his generosity and the SDG unanimously endorsed the proposed inscription.

**Summing up**

LF thanked everyone for coming.

**Future meetings**

- **13 May 2008, 1pm – 4pm**
- **30 September 2008, 1pm-4pm**