

Minutes of the 10th Meeting of the Strategy and Development Group of the James Lind Alliance, Royal Society of Medicine, 27 September 2007

Participants:

Ms Patricia Atkinson	Administrator, James Lind Alliance Secretariat
Sarah Buckland (Attended on behalf N Partridge)	INVOLVE Support Unit
Sir Iain Chalmers	Editor, James Lind Library
Mrs Sally Crowe	Director, Crowe Associates
Mr Lester Firkins	Business consultant, Medical Research Council
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Prof Stephen Holgate	Physician, Southampton General Hospital
Dr Susan Kerrison	Assistant Director Research and Development University College London Hospitals Trust
Dr Sandy Oliver (Joined the mtg at 3pm)	Editor, Cochrane Consumers & Communication Review Group
Dr Sophie Petit-Zeman	Head of External Relations, Association of Medical Research Charities
Dr John Scadding	Dean, Royal Society of Medicine
Dr Peter Sneddon (Attended until 2.10pm)	Head of Research Programmes, Department of Health
Ms Ruth Stewart (Attending on behalf S. Oliver)	Assistant Director, Social Science Research Unit, Institute of Education, University of London
Dr Mark Welfare	Gastroenterologist/senior Lecturer Northumbria Healthcare NHS Trust
Ms Philippa Yeeles	Programme Manager, UK Clinical Research Collaboration

Invited Guests:

Dr Douglas Grindlay	Dermatology Information Specialist, NLH Skin Disorders Specialist Library, Centre of Evidence Based Dermatology, University of Nottingham
Prof Hywel Williams	Clinical Lead, NLH Skin Disorders Specialist Library, Centre of Evidence Based Dermatology, University of Nottingham

Apologies:

Prof Glyn Elwyn	Chair, Primary Care, Cardiff University
Dr Marianne Miles	Patient/Public Liaison Lead, UK Clinical Research Network
Mr Nick Partridge	Chair, INVOLVE
Dr David Tovey	Editor, <i>Clinical Evidence</i> , <i>BMJ</i>
Dr Chris Watkins	Board Programme Manager, Medical Research Council
Ms Pamela Young	Senior Programme Manager, National Coordinating Centre for Health Technology Assessment

1. Welcome from the chair

SC welcomed members to the 10th meeting of the James Lind Alliance (JLA) Strategy and Development Group (SDG). SC said that Charles Warlow and Marcia Kelson have stepped down due to other commitments. Charles will continue to offer his support with Epilepsy. Marcia has offered continued support via the Patient and Public Involvement Unit at NICE. SC will write and thank them both for their valuable input.

LF will contact Mike Rawlins, NICE to find out if they have anyone who would be willing to sit on the JLA SDG, possibly a non-staff/non-executive member, who will not necessarily formally represent the views of NICE but who could add an experienced perspective.

Action: LF

2. Minutes of 19 June 2007

The minutes of the last meeting were accepted.

Matters arising:

Item 4, DUETs progress report – Action for IC related to DUETs, dealt with in item 4 of

these minutes.

3. Working Partnerships update

Asthma – SC said that a meeting with representatives of the WP has been scheduled for 9th October to finalise vignettes for the top ten treatment uncertainties. This will enable presentation/dissemination to a wider audience/funders. The BMJ article is in its final iteration and will be submitted by the end of October.

In future, when Stephen Holgate, president of the British Thoracic Society (BTS) and chair of the UK Respiratory Research Collaborative, is unable to attend JLA Working Partnership meetings, he will be represented officially by Colin Gelder, Consultant Respiratory Physician and editor of the DUETs asthma module. Colin has suggested a partnership between the BTS and the British Lung Foundation on – COPD (Chronic Obstructive Pulmonary Disease), and, with support from Stephen, he has written to the prospective participants/organisations. MW suggested that the asbestos-related lung disease organisations should also be contacted.

Incontinence – LF gave a brief update on the development of the Incontinence WP and said that there were 18 groups/individuals involved and that the challenge was ensuring they retain ownership. LF said that a small group was being convened to manage the harvesting of the questions, with input from Mark Fenton. Some guidance notes were currently being put together. The question of a NLH Specialist Library home for the uncertainties was raised. IC reported that the Clinical Lead for the Kidney Diseases Specialist Library had expressed willingness to incorporate a DUETS Incontinence module under its aegis. LF and IC to discuss this further.

Action: IC & LF

Epilepsy – LF said there was nothing new to report but that Epilepsy would be taken forward as a DUETs module and that there was no immediate role for a JLA WP (but this may be considered at later stage).

Diabetes - JH said there was not much to report, but the NLH Specialist Library for Diabetes has had some input from a previous meeting on understanding how DUETS and the JLA works.

Vitiligo - The initial bid has reached the second round. The full bid is currently being written up, to include funding for DUETS and a JLA WP. SC will keep the group informed.

4. DUETs – Progress towards DUETs modules

IC gave a brief report on DUETs progress, and responded to issues raised at the previous SDG meeting as follows:

1. *Flag JLA prioritisation process on DUETs website* – This is in hand.
2. *Explore how groupings of similar uncertainties could be displayed* – This is up to the prioritisation process to take forward and will not be done by DUETs.
3. *Show traffic to DUETS from NLH site* – Not yet done, but will be taken forward.

Iain said that there were six Pioneer NLH Specialist Libraries developing DUETS modules, of which the Skin Disorders Library was one (there are 27 Specialist libraries in all). Iain also said that all new contracts for the NLH Specialist Libraries will include a requirement to work with DUETS.

Hywel Williams and Douglas Grindlay gave a presentation entitled "Experience of the Skin Disorders Specialist Library in developing a community of practice and compiling the DUETS Skin module"

Abstract of the presentation as follows: (the presentation will be put on the JLA Website alongside the agreed minutes of this meeting)

The NLH Skin Disorders Specialist Library is a "One-stop" shop for quality, evidence-based information on skin conditions and treatment. It is based at Centre of Evidence Based Dermatology, University of Nottingham, which also

hosts the Cochrane Skin Group and UK Dermatology Clinical Trials Network—this gives excellent opportunities to work together and co-ordinate activities.

Like other NLH Specialist Libraries, the Skin Disorders Specialist Library has a large Stakeholders Group, including secondary care clinicians, GPs, nurses, health information specialists and patient support groups. Its wider community of users includes health professionals in the UK and abroad, as well as patients and the wider public. The monthly e-mail updates have nearly 500 subscribers, including a large proportion of UK dermatologists.

Means of communication with our users include:

- The Stakeholders Group (formal meetings and individual correspondence)
- The Library itself, especially home pages
- National Knowledge Weeks
- Monthly e-mail updates
- The feedback form on Library home page
- Talks and stands at conferences
- Articles in journals and newsletters

The implication for DUETs and the JLA is that NLH Specialist Libraries are well placed to communicate with their communities of practice, and can act as the centre of a network for collection of uncertainties and for research prioritisation. The libraries also have great potential for dissemination.

Discussion on patient questions that were not uncertainties

There was a general debate on what happened to questions that were not uncertainties eligible for inclusion in DUETs, but uncertainties as expressed by patients. The following comments were made:

- What happens to uncertainties that were not treatment uncertainties? (unknown knowns)
- The relevant information should be fed back to the relevant patient and clinician organisations.

LF used the JLA Research Cycle paper to demonstrate how the JLA WPs and DUETS work with uncertainties, and said that it had been left to the people/organisations forming the WP to feed back any known answers, where possible. LF and IC both explained that this was not currently within the focus/funding of the JLA or DUETs. SC explained that Asthma UK had taken these 'unknown knowns' seriously, and staff on their advice line had contacted 40 or so people (where they had identified themselves) to fill the information gap and advise.

The general consensus was that this was unfinished business and warranted further thought and discussion, and that the JLA could help by drawing attention to the issue, and pointing to the lack of coherent strategies for meeting patients' needs to know about 'unknown knowns'. This issue will be incorporated in the discussion meeting set for 17 December, as detailed in item 6.

5. JLA Objectives

1. Explore with the Clinical Research Networks how research priorities are identified

SC gave an update on the progress 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'. SC said that INVOLVE, AMRC, UKCRC, and UKCRN were also in the process of doing projects looking at similar but complementary themes. SC said that the project leads have been asked to liaise to share data and findings from their respective studies to ensure no overlap. The timelines will be staggered so that data from each project can be used to inform the next, and to avoid bombarding research funders with similar

initiatives!

The following is a brief overview of the projects:

INVOLVE: INVOLVE are leading on a joint project (with JLA, AMRC & UKCRC) to survey public involvement in health research commissioning and funding processes. Contact Maryrose Tarpey. Pilot nearly ready and it is hoped that the return data will be ready to be shared with the JLA project team by end of this year.

JLA: Rapid appraisal of key publications on research priority setting, interviews with sample (15) of research funders on how they set priorities, and how they involve patients in this, followed by in-depth work with a smaller sample. Contacts, Sally Crowe and Kristina Staley. Plans have been agreed, the project is due to start October 07, and be completed in April 2008. The JLA sample will not be contacted until data are available from the INVOLVE study.

UKCRN: Mapping of PPI activities in UKCRN networks - still at planning stage. Contacts: Marianne Miles and TwoCan Associates.

UKCRC: PPI Activities Log - which is in the process of being updated – TwoCan Associates will use this as a resource for the JLA work. Contact, Philippa Yeeles. <http://www.ukcrc.org/patientsandpublic/currentppiprojects/activitieslog.aspx>

AMRC: A PPI action learning set for a selection of AMRC member charities (i.e. proactive learning of organisational PPI in research) to start later this year. Contact, Simon Denegri, Chief Executive of AMRC.

2. ***Collaborate with other organisations in organising two symposia to discuss issues relevant to the JLA's objectives***

Joint JLA/Lancet conference: How can clinical trialists serve the needs of clinicians and patients more effectively?, 25 June 2007, RSM. The seminar went very well and the evaluations received were very encouraging. Reports of the meeting are available for viewing on the JLA website. http://www.lindalliance.org/JLA_LANCET_Event_June2007.asp

Joint JLA/AMRC symposium: Should patients tell researchers what to do? If so how?, 17 September 2007, Wellcome Collection Conference Centre. The seminar went very well and the evaluations received were very encouraging. Reports of the meeting are available for viewing on the JLA website. http://www.lindalliance.org/JLA_AMRC_Event_Sept2007.asp

Proposed Seminars for 2008

'Patient-reported Outcome Measures versus Patient-important Outcome Measures' Seminar. Agreed that the PROMs seminar will be scheduled for Autumn 2008. To be discussed in further detail at a later date.

The SDG to be asked to decide which of the following should be the 2nd JLA seminar for 2008

Transparency in research - Joint JLA/AMRC/ Health Coalition Initiative Seminar (The Health Coalition Initiative is a network of voluntary health organisations and pharmaceutical companies (<http://www.healthcoalitioninitiative.org.uk/>)). NP will contact Richard Tiner, ABPI and Simon Denegri, AMRC (which has produced a transparency guidance report), and will find out more and discuss the proposed seminar. The JLA may need guidance on the scope of the seminar. It was suggested that the UKCRC be involved to assist with this.

Action: NP (from last SDG minutes)

Integrating treatment evaluation within routine clinical practice - Joint JLA/GMC seminar 2008/9

"The GMC recently reissued its booklet 'Good Medical Practice', which now contains encouraging words on the duty of doctors to play their part in addressing

<p>uncertainties about the effects of their treatments. The GMC is currently receiving evidence on its plans to update its booklet on Informed Consent. Given the success of the joint James Lind Alliance/Lancet meeting and the encouraging reactions to the joint JLA/Association of Medical Research Charities meeting, it might be worth exploring the possibility of a joint JLA/GMC meeting on 'Integrating treatment evaluation within routine clinical practice'.</p>
<p>3. <i>Explore whether some medical research charities/other funders can extend JLA methods. (via Affiliates or other networks)</i> <i>Extending and assessing the bibliography in preparation for a systematic review</i> £15,000 has been allocated to fund the start of this project, and the JLA will assist in seeking further funding to take this forward. Ruth Stewart and Sandy Oliver presented a paper outlining the tasks required for this work and a list of potential funders. After discussion, SO and RS were asked to amend their proposal to incorporate the agreed suggestions, and resubmit to SC for further discussion and agreement. SK was asked to supply references for her comments about the methods of patient and public involvement. Action: SO & SC</p>
<p>4. <i>Conclude the priority setting cycle of the JLA Asthma Working Partnership</i> Objective met</p>
<p>5. <i>Establish two further JLA Working Partnerships</i> Objective partly met – This item is dealt with in more depth in item 3 of these minutes.</p>
<p>6. <i>Adopt the lessons learned from the piloted working partnerships and other models</i> LF has produced a paper 'JLA another way of thinking – the research cycle'. He gave an overview of this paper which offers an illustration of how the JLA process fits with the 'Research Cycle' in item 4 of these minutes.</p>
<p>7. <i>Review the resources needed to achieve successful partnerships</i> Nothing new to report at this time</p>
<p>8. <i>Funding Secured to support the continued development of the JLA from 2007 to 2010</i> To be reviewed yearly.</p>

6. JLA Objectives for 2008 - 2011

This item was only briefly discussed due to lack of time. There were many issues raised and it was agreed that this topic warranted more time, so the group agreed to a meeting in December dedicated to discussing the future objectives of the JLA. The following are some of the points/comments raised:

- Developing a typography of research prioritisation
- Winning over the researchers
- Targeting influential researcher/funder to take patients' views seriously
- Increasing patient numbers in trials and developing trials
- Targeting the regulators, who are conservative
- Focussing on patient-important outcome measures
- Moving away from an 'organ centred' approach to health and disease to multi-system effects
- Quality of life data
- Return to the JLA founding principles – are priorities different? Do the priorities influence the agenda, if so how? Are patient's priorities reflected in research funding? Do findings of research lead to better treatments and health?
- Focus on fully worked WP's to show that it can work

- Can the fruits of DUETs and WP's attract funding? If not, how can the JLA change this?
- Integrate our methods with others, who are undertaking priority related activity to produce an overview of methods and approaches
- Analyse feedback from the seminars – there will be clues for action in these notes!
- Aim for 1 example of a shared priority for research that is funded
- Developing Working Partnerships (they take time)
- Finish the unfinished business of WPs – Consider how best to present top ten uncertainties to relevant research funders
- Look at the journey that DUETs and WP have made – what can we learn from this and celebrate it
- Target the UK Respiratory Research Collaborative
- Convert 1 or 2 influential people in research to the JLA cause – e.g. Mark Walport, Wellcome; John Bell, Academy of Medical Sciences
- Act as a 'ginger group' for change; don't compromise on ideals and philosophy

Summing up

SC thanked everyone for coming, and said that the feedback was extremely helpful. She suggested that the key actions are:

1. Finalise the commissioning of the priority setting mapping exercise and extending the bibliography
2. Continue the discussion about objectives for the next two years and present a draft plan for the January meeting
3. Address the 'unknown knowns' in a wider context with dialogue with other interested parties
4. Build on the excellent seminar series

Future meetings

- **17 December 2007, 10:30am - 1pm (Planning JLA Objectives 2008/11)**
- **14 January 2008, 1pm – 4pm**
- **13 May 2008, 1pm – 4pm**