

Minutes of the 13th Meeting of the Strategy and Development Group of the James Lind Alliance, Royal Society of Medicine, 30 September 2008

Participants:

Ms Patricia Atkinson	Administrator, James Lind Alliance Secretariat
Miss Lizzie Amis	Project Manager, Patient and Public Involvement Programme, NICE
Dr Brian Buckley	Primary Care Researcher, Cochrane Fellow and Chairman of Bladder and Bowel Foundation (formerly Incontact and the Continence Foundation)
Sir Iain Chalmers	Editor, James Lind Library
Mrs Sally Crowe	Director, Crowe Associates
Mr Lester Firkins	Business consultant, Medical Research Council
Prof Stephen Holgate	MRC Clinical Professor, University of Southampton
Dr Susan Kerrison	Assistant Director Research and Development University College London Hospitals Trust
Prof 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 Peter Sneddon	Head of Research Programmes, Department of Health
Mr Roger Steele	Patient & Public Involvement Manager, UKCRN.
<i>(Attending on behalf R Wilson)</i>	
Mrs Jenny Versnel	Executive Director of Research and Policy, Asthma UK
Ms Philippa Yeeles	Programme Manager, UK Clinical Research Collaboration
Ms Pamela Young	Senior Programme Manager, National Coordinating Centre for Health Technology Assessment

Apologies:

Prof Glyn Elwyn	Chair, Primary Care, Cardiff University
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Dr David Tovey	Editor, Clinical Evidence, BMJ
Dr Chris Watkins	Board Programme Manager, Medical Research Council
Mr Roger Wilson	Associate Director PPI, UKCRN; Consumer Member, NCRI Sarcoma CSG; Chair, Prevention Research Advisory Board, NPRI.

Invited Guests:

Dr Ruth Stewart	Assistant Director, Social Science Research Unit, Institute of Education, University of London
Ms Katherine Cowan	Research and Consultancy

1. Welcome from the chair

LF welcomed new members, and invited guests to the 13th meeting of the James Lind Alliance (JLA) Strategy and Development Group (SDG). LF said that, due to his promotion within the MRC, Chris Watkins has stood down from the SDG and the James Lind Initiative/JLA Project Group. The SDG is very sad to see him go as his input has been invaluable. He has been replaced by Morven Roberts, Clinical Trials Manager, MRC.

2. Minutes of 13 May 2008

The minutes of the last meeting were approved.

3. Outcomes in Clinical Research – whose responsibility? – Meeting, 20 Nov 2008

The meeting is being run by the JLA in collaboration with the Social Science Research Unit (SSRU) and the Royal College of Nursing Institute (RCNI). The maximum number of participants has been reached and registrants include researchers, patients and support groups, and clinicians. There will be oral presentations during the morning session. The afternoon session consists of poster presentations of worked examples of outcome

development.

SO has drafted a survey that will be sent to all delegates prior to the event, asking them to specify: 1) Their preferences for engagement, and 2) methods and markers of success in terms of processes and outcomes. SO will analyse the results before the meeting.

The subject of this conference has proved to be quite topical. The MRC also has an initiative around patient-reported outcomes, and the JLA has been invited to contribute. The first stage of this initiative involves a workshop later this year or early next year. Health Care Events is also hosting an event with a similar theme (*'Clinical Outcomes using Patient Reported Outcome Measures'*) on the same day as the JLA meeting, and, due to popular demand, this event will be repeated in Manchester in January 2009. The JLA has been invited to contribute to the latter.

4. JLA Annual Report

The annual report has been submitted to DH and MRC.

5. Urinary Incontinence – What Harvesting uncertainties feels like

BB gave an overview of the Harvesting process which is currently in progress. BB said that, out of the 30 organisations contacted, 22 accepted the invitation to work with the partnership. Some of the organisations were more involved than others. BB, LF & Adrian Grant have been the main leads and have taken a pragmatic approach and worked with the most enthusiastic groups among those who want to participate.

BB felt that more clarity was needed in defining/understanding the role of the JLA in the partnership.. Another problem was the extent of communication from the interested organisations: some were more active than others, and it would be useful to incorporate this into the JLA tool kit, with guidelines on what is expected of participating organisations. BB and Adrian Grant also found problems with some aspects of data input to DUETs. BB will send some suggestions to IC.

Action: BB

BB said there were 417 questions/uncertainties submitted by patients, carers or clinicians, of which 363 were eligible for inclusion. In addition, 100 uncertainties were derived from Cochrane reviews and other sources. A list of 226 uncertainties, together with guidance notes, were sent out to 21 organisations, which were being asked to identify and submit their top 10 priorities. BB and Adrian Grant will use these returns, together with weightings derived from other factors to determine the top 30 to be considered at the prioritisation meeting. BB has begun drafting a paper to describe the prioritisation process. BB will be presenting the process/progress of the UI Working Partnership at the Annual Meeting of NICE (alongside LF and Adrian Grant), and at several other conferences. All of the submitted uncertainties will eventually be published in DUETs.

There was a general discussion about the extent to which the JLA should reconsider its current position that its involvement should cease after the prioritisation process had been completed, and possibly assist partnerships in securing funding. It was suggested that the JLA needs to raise this issue with the DH and MRC because, if agreed, it would have resource consequences.

6. Asthma Working Partnership - Is there life after JLA?

JV and SH reported activities by the Asthma Working Partnership after the conclusion of the prioritising process as follows:

JV said that Asthma UK has been working up each of the ten priorities into EPICOT format, with the aim of providing some contextual information from the different responses received on a topic for people with asthma.

A large survey has also been initiated on concerns related to potential side effects of both oral and inhaled steroids for asthma. A questionnaire was developed and mailed out with the Asthma UK magazine and placed on the website. To date, approximately 3,000

responses have been received. The questionnaire for healthcare professionals is currently being developed. It will obviously take some time to analyse these results but it is hoped that this will be a useful contribution to understanding concerns side effects of steroids, and identifying appropriate action.

Asthma UK is also considering developing the (top ten) breathing exercises questions and allocating funding to research these outside their usual grant round. Asthma UK currently has two research strategies, one for basic research and another for clinical research, each with its own priority areas. In the new strategic plan beginning October 08, they will move towards developing a single research strategy and the JLA priorities will feed into this.

SH said that the JLA priority setting exercise in asthma had identified a series of research questions that certainly would not have been identified otherwise. Of particular interest is the selection of drug-related side effects, breathing exercises in treatment and the different ways to treat severe asthma. SH is delighted that the HTA is taking forward several of these to work them up into researchable questions with strong justification.

IC asked that, in future, harvesting questionnaires should ask respondents for permission to make available their own words through DUETs, so that there would be an audit trail showing how their words had been interpreted in the brief summary statements used in the DUETs main records.

GE/SH have written an article for *Thorax* (a respiratory medicine journal) relating to the success, highlights and important learning experience of working with the JLA. SH will let the JLA know when it is published.

Diabetes

SC & BB have met with Sarah Johnson, Director of Policy and Communications Juvenile Diabetes Research Foundation. The Foundation is interested in working with the JLA on uncertainties of treatments for Type1 Diabetes. It was suggested that Jennifer Preston, Consumer Liaison Officer, Medicines for Children Research Network, would be a good contact and that SC should also get in touch with the National Children's Bureau (NCB), which has experience of consulting with children and young people.

Working Partnerships update

Asthma

- Paper submitted for BMJ on 6th May 2008 – rejected – for submission elsewhere led by GE/SH
- Impact of top uncertainties on asthma research to be discussed at Strategy and Development Group
- JLA still pursuing Respiratory Specialist Library to host asthma findings
- Asthma UK undertaking Side Effects Project (patient adherence and compliance) started in summer 2008
- UK Respiratory Research Collaborative Prioritisation Exercise – and JLA Prioritisation “widely disseminated to NIHR Local Comprehensive Research Networks and NIHR Biomedical Research Centres and Units” Stephen Holgate July 2008

Urinary Incontinence

- Harvesting process complete – 226 uncertainties
- These are now with 21 “Organisations” for ranking into their top 10 – closing date for submission 9th October 2008
- Lead team then review and sort into an unranked top 30 – and send back to participating organisations
- Final priority setting meeting 6th November 2008

Diabetes

- Diabetes SL hosting a meeting on 13th May 2008 to explore input to Diabetes DUETs module.
- Long list of people interested in WP and good links with Diabetes NCRN established

Epilepsy

- Funded DUETs resource available in Swansea under management of Mark Rees, Keith Lloyd and Matteo Cella
- Katherine / Lester/ Mark liaising with clinicians to schedule a meeting where the development towards a JLA WP can commence.
- JLA-funded Patient View survey now complete and ready for publication

Schizophrenia

- Uncertainties already entered on DUETs
- JLA asked for support in priority setting process
- Meeting held in Swansea 25th June with LF, KC, Keith Lloyd, Matteo Cella, Mark Fenton (telecon) and Clive Adams (telecon)
- The group agreed to develop a priority setting process for the schizophrenia treatment uncertainties on DUETs
- The group is drawing up a long list of possible priority setting partners

Vitiligo and Eczema

- Research for Patient Benefit Programme bid successful
- SPRUCD Setting Priorities for People with Skin Disease
- First full project team meeting mid-September – very positive
- Work to start on Vitiligo first, with systematic review and harvesting of uncertainties in late 08/early 09, with eczema to follow later in 2009

Chronic Obstructive Pulmonary Disease (COPD)

- Uncertain future (Colin Gelder not now proceeding)

Interstitial Lung Disease

- Such as idiopathic pulmonary fibrosis and sarcoidosis.
- Dr Nik Hirani, Senior Lecturer and Honorary Consultant in Respiratory Medicine
MRC/University of Edinburgh Centre for Inflammation Research
- Mark Fenton liaising with Nik Hirani on developing modules for DUETs.
- NH still seems eager – and will revert to MF when early meetings have been arranged with interested parties.

7. JLA Toolkit - for future Priority Setting Partnerships

KC is in the early stages of producing the toolkit. Before it can be designed, certain questions must be addressed about prime audience; paper/virtual; and length and depth of information. KC suggested that it needs to be planned as if the JLA were no longer in existence. SC said that the toolkit should also include what other groups are doing on priority setting. It will be developed over the next 18 months.

KC has set up an on-line survey for Priority Setting Partnerships to feed back after the prioritisation process. This information will be taken into account in developing the toolkit. The on-line survey will be launched for use by the Urinary Incontinence WP after the completion of their prioritisation process. KC asked members of the Asthma WP to test the system.

8. Social Science Research Unit update – A systematic map of studies of patients' and clinicians' research priorities

RS presented her and SO's systematic map of the literature on patients' and clinicians'

research priorities. This showed that, despite policy support for patient and public involvement within health research, involvement rarely extends to influencing research agendas. Furthermore, clinicians and patients seldom work together to identify and prioritise research. This review of the literature had made clear that the JLA's priority setting partnerships are highly distinctive.

Following discussion of the presentation the following was agreed:

- RS to finalise a summary of the full report to send to Alex Markham, copied to Liam O'Toole. This would be sent with a letter co-signed by LF and SO.
- RS to work on finalising the report so it can be published on the JLA website.
- RS and SO to work on submitting the work for publication in a journal (maybe BMJ)

JS is keen to see the full paper submitted to a prominent journal. LF will talk to RS & SO to discuss strategy for moving forward. RS to send copies of her PowerPoint presentation to SPZ to put in the AMRC members briefing.

Action: RS

9. Priority Setting Mapping Project (PPI)

SC gave an overview of the project and said that TwoCan will present their findings in full at the next SDG meeting.

10. DUETs update

IC said that the current James Lind Initiative funding ends in 2010, and that he will be submitting a report to the MRC/DH Project group detailing the work of the last 18 months. The report will include a proposal to extend the work of the JLI (which includes DUETs and the continuation of the JLA secretariat) until 31 March 2013.

Speaking on behalf of the Department of Health PS said that, having looked at a draft report previously sent and discussed with Sally Davies, the Department is pleased with the progress and work done so far, and wish to be as supportive as possible going forward. He did not foresee any problems.

IC said that from April 2008 the Specialist Libraries in the National Library for Health have been contracted to develop DUETs modules. The infrastructure of DUETs has now been transferred into the National Library for Health. Following an announcement from Lord Darzi saying that clinicians should be provided with better evidence, a new service called 'NHS Evidence' is being developed under the aegis of NICE and will incorporate the NLH Specialist Libraries. DUETs will be an integral element in NHS Evidence.

LF has accepted an invitation from NICE to join the Advisory Board for NHS Evidence. (SO and IC have also been invited and have accepted)

SO asked IC what opportunities there were for DUETs modules to be formed by people outside of the NLH network, what the connections were between the different modules and the technical aspects. There seemed to be a lack of communication between people involved in the various DUETs modules. IC said that the DUETs development group last met a year ago, and that a DUETs Pioneers Group, made up of Specialist Libraries which had shown a particular interest in developing modules, had been convened to help each other. A NLH Working Group devoted to DUETs has now been formed. It was suggested that a forum is needed for people outside this network .

NP said that the possibility of scaling up DUETs and the Working Partnerships by linking to NHS Evidence was exciting and a huge prize, with the Darzi review behind it. He said it should be embraced and that the JLA should not be shy in asking for more resources to deliver best value in the years 2010 – 2013.

SO said that the NICE Citizens Council is in favour of NICE being bolder in stating when there isn't enough evidence. LA said that NICE is developing quickly and that the NICE Tool section would work well with the JLA and that there are close links with NHS Choices

as portal for the public.

11. Affiliates – What about controversial applications?

Due to lack of time this item was not discussed but will be carried forward. The following is the issue that would have been raised. 'Currently all Affiliate applications are granted automatically, and Affiliates website addresses are listed on the JLA website, and conversely they can cite being affiliates of JLA on their websites, even if the work they do could be controversial/not aligned with the work of the JLA. It was felt that this policy should be reviewed'.

Summing up

LF thanked everyone for coming.

Future meetings:

23 January 2009

PA will contact SDG members to arrange meeting date for May 2009