

Minutes of the 4th Meeting of the Steering Group of the James Lind Alliance, Royal Society of Medicine, 19 January 2006

Participants:

Ms Patricia Atkinson	Administrator, James Lind Alliance (JLA) Secretariat
Sir Iain Chalmers	Editor, <i>James Lind Library</i>
Mrs Sally Crowe	Director, Crowe Associates
Mr Mark Fenton	Editor, DUETs (Database of Uncertainties about the Effects of Treatments)
Mr Lester Firkins	Business consultant, Medical Research Council
Dr Anthony Harrison	Senior Fellow, King's Fund
Ms Jenny Hirst	Chair, Insulin Dependent Diabetes Trust
Dr Marcia Kelson	Associate Director, Patient and Public Involvement Programme, NICE
Dr Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Mr Nick Partridge	Chair, INVOLVE
Dr Sophie Petit-Zeman	Director of Public Dialogue, Association of Medical Research Charities
Dr John Scadding	Associate Dean, Royal Society of Medicine
Dr Peter Sneddon	Head of Programmes, R&D Division, Department of Health
Dr Chris Watkins	Trials Manager, Medical Research Council

Apologies:

Prof Glyn Elwyn	Chair, Department of Primary Care, Cardiff University
Prof Stephen Holgate	Professor Respiratory Medicine, Southampton General Hospital
Mr David Tovey	Editor, <i>Clinical Evidence</i> , BMJ
Jenny Versnel	Assistant Research Director, AUK
Prof Charles Warlow	Neurologist, Western General Hospital NHS Trust, Edinburgh
Ms Maxine Whitton	Member, Cochrane Skin Group

1. Welcome from the chair

Sally Crowe welcomed members to the fourth meeting of the James Lind Alliance (JLA) Steering Group (SG). SC explained that the agenda for the meeting would follow the objectives as outlined in the draft Steering Group report on the development of the JLA during 2005/05.

2. Minutes of 13 September 2005

Accepted, with a minor correction.

3. JLA Report, Objective 1: JLA objectives and report on JLA Development Group

LF reiterated the objectives of the JLA (as outlined in the JLA literature), and said that the JLA Development Group is looking to support the delivery of the objectives for 2006, with guidance from the SG.

4. JLA Report, Objective 2: Database of Uncertainties about the Effects of Treatments (DUETs)

MF gave a progress report and presentation of DUETs and the website. MF said that the database would shortly be updated in light of an evaluation of the website presented at a meeting of the DUETs Development Group on 16 January. Some of the feedback received made clear that it needs to be made more explicit that the DUETs is a resource to help prioritise new research, and that it is still in a pilot phase.

As explained in Annexe 7 of the draft report, IC felt that, if opportunities presented themselves, the contents of DUETs should be extended independently of the development of JLA Working Partnerships' (WP), thus 'uncoupling' the development of DUETs from the speed with which JLA WPs developed. The Steering Group supported this decision after being reassured that JLA WPs would receive attention from the DUETs

team as they emerged. This work would contribute to raising awareness of treatment uncertainties.

SC suggested that DUETS could benefit from working with UK Prostate Link (www.prostate-link.org.uk). The website is a gateway that provides links to quality-assessed information about prostate cancer. The questions received are from clinicians patients and carers. This will be investigated further.

Action: SC

5. **JLA Report, Objectives 3 and 6: Communications**

Mass mailings and website - PA said that the aim of the mass mailing was to invite interested parties to Affiliate to the JLA, showing that they support its objectives. From some of the enquiries received it was clear that the reason for affiliation was not apparent to everyone. It was decided that future communications would be rephrased. The mailing created considerable interest: nearly 70 organisations and nearly 30 individuals had affiliated to the JLA. The website has been updated to list all of the organisations affiliated and those individuals who have given permission. PA said that that she would welcome feedback and ideas for new data for the website.

Action: JLA Dev Group

MK said that the PIN (Patients Involved in NICE) group would be very interested in the JLA. MK to advise PA of the next PIN meeting and a contact person.

Action: MK

Presentations at meetings – Members were referred to Annexe 9 of the JLA Report and asked to inform PA about any additional talks that had promoted the work of the JLA.

NICE Conference and JLA Annual Meeting, 2005 [Annexes 10, 11,12, JLA Report]. Both meetings had been successful (more information could be found in the annexes listed above).

NICE Conference, JLA Annual Meeting and possible other JLA meetings, 2006

There was discussion on how and where to hold future JLA meetings, taking account of venues and cost relating to the different audiences. Although the NICE meeting is a good venue, the cost of attend is prohibitive for many patient groups, even though there are some bursaries available. There was further discussion about whether to abandon the notion of a JLA Annual Meeting. An alternative was to consider concentrating on shorter sessions, with a particular focus, at other meetings, in collaboration with other organisations. PS suggested approaching the Wellcome Trust for support as they currently sponsor public involvement events. The issue was referred to the JLA Development Group for further consideration. However it was agreed that a plenary session at NICE was an efficient way of taking stock of progress. IC was asked to contact NICE to request future JLA 'slots' at the annual Clinical Excellence meetings.

Action: IC & JLA Dev Group

IC drew attention to the short bibliography of studies eliciting therapeutic questions and treatment outcomes of importance to patients and clinicians (Annexe 11) and said that he felt a thorough search for and systematic review of all such studies would be worthwhile. CWat noted that the MRC currently had a call for proposals on methodology research on the implications of research (the deadline for outline proposals is 27 February, and for full proposals 1st March). SO said that she would be interested in carrying out this piece of work, and she will discuss further with IC.

Action: IC & SO

Published articles about the JLA Members were asked to identify omissions that should be added to the list of articles in Annexe 13 of the JLA Report.

6. **JLA Report, Objective 4: Working Partnerships**

Asthma: [Annexe 15, JLA Report]

LF summarized the progress so far in developing the JLA Asthma WP involving Asthma UK (AUK) and the British Thoracic Society (BTS). LF spoke on behalf of Jenny Versnel, who was unable to attend the meeting due to illness. AUK are progressing well with the compilation of views and questions. Questionnaires are due to go out to a potential audience of circa 4000 in the next month, this will hopefully engage with a wide and varied audience, which includes children. The AUK website is under review to consider how it can be used to garner more information. INVOLVE and particularly Philippa Yeales have been of great help in both these aspects. Jenny Versnel expects the full results to be available by early spring.

SC reported that the Asthma WP, 8 Dec 2005 meeting, although difficult at times, went well. Agreement was reached to populate the DUETs database from the clinicians perspective and Toby Lasserson, from the Cochrane Airways Group, will gather questions from specialist nurses. A 'first pass meeting' of the partnership is to be organised in the next 2/3 months to assess the DUETs questions for suitability. It was also agreed that one final planning meeting be convened before the main priority setting meeting. The challenge for this partnership is to ensure that these plans are acted on. SC and LF will keep a close eye on developments and enlist the explicit support of Stephen Holgate. The group agreed to continue the support for the Asthma WP, and to ensure that the challenges and successes are captured so that other WP's can benefit from this experience. PA will circulate a copy of the notes of the meeting to the SG.

Action: SC, LF, SH & PA

LF raised the Question "what would success look like?" The following are some possible answers to this question:

- Effective process for WP
- List of research priorities
- Funded research priorities
- "Sense of rightness"

PS reminded the group that there was no substitute for face-to-face dialogue, and that the WP process should be pursued, if only to "learn whilst we fail". He also reminded the group that the current changes to the R & D landscape are a positive environment for initiatives such as the JLA.

Epilepsy: [Annexe 16, JLA Report]

JS said that he had had a teleconference with a group of clinicians who are enthusiastic about the JLA. A letter will be drafted by CWar and JS (to be co-signed also by LF) to the Joint Epilepsy Council (JEC), which is an umbrella organisation for epilepsy patient organisations, to seek its views and gauge its enthusiasm for forming a WP. SP reminded the group that it would be worth contacting the Brain and Spine Foundation. It was suggested and agreed that SP be involved in the Epilepsy process.

Action: JS, CWar, LF & SP

Current JLA process: JLA Objective 5]

LF directed the group to Annexe 17 of the JLA Report, which shows a flowchart of the current JLA pathway to the priority setting process.

Other possible approaches to operationalising the JLA concept

It was agreed that JLA was not wedded to a particular process for pursuing its main objective, and should consider other possible models, drawing on lessons learned from the piloted WPs.

UK Clinical Research Networks

IC said that he thought it important to ask how research priorities are being identified by

the Clinical Research Networks, and assess the extent to which they are endeavouring to identify the shared priorities of patients and clinicians. He has been in touch with Peter Selby, Janet Darbyshire, Liam O'Toole, Matthew Hallsworth, Til Wykes, Ros Smyth and Keith Lloyd, about this and will continue to endeavour to promote JLA principles with them and others.

Action: IC

OMERACT

One of the most successful elements of the 3 December JLA meeting was a joint presentation made by John Kirwan (a rheumatologist) and Enid Quest (a patient with rheumatoid arthritis). This presented an account of the way that the involvement of patients in the OMERACT (Outcome Measures in Rheumatoid Arthritis Clinical Trials) Group had led to the identification of a symptom (fatigue) that patients rated as even more important to them than pain. The problem of fatigue had been almost completely unrecognised by researchers. It was suggested that JK and EQ might be asked whether they would be willing to film their presentation for use by the JLA.

IC had asked JK whether he and EQ would be interested in helping to establish a JLA Working Partnership in arthritis, involving two or more clinician and patient organisations. JK's advice was that this was an inefficient way of making progress, and that it would be better to begin with clinicians and patients who were already working together, as was already happening in Bristol. IC will write to JK and EQ, re the JLA's interest in OMERACT and the way their partnerships work, and if they are interested, LF will meet with them.

Action: IC & JLA Dev Group

SO mentioned **BDF Newlife Foundation** (www.bdfcharity.co.uk) which is a UK birth defects and child health research charity with an interesting way of interacting and recruiting families into research projects. SO suggested that she could talk to Sheila Brown, Chief Executive of BDFN, about funding research on what patients want. Some of the questions raised could be used to populate DUETs. SO will investigate this further and provide feedback.

Action: SO

7. JLA Report, Objective 7: Proposed extended funding for JLA Secretariat and DUETs

IC explained that the progress reports of the JLA and DUETs over the last two years would be elements of a wider ranging report for the MRC/DH, covering all the work he and Patricia Atkinson had been doing under the aegis of the James Lind Initiative since July 2003. This would include a proposal to extend support for this programme of work (which included the JLA Secretariat) until 31 March 2010.

Action: IC

8. Influencing objectives for JLA

The other activities intended to promote the objectives of the JLA were outlined as presented in Annexe 18 of the JLA Report.

9. Proposed JLA objectives for 2006 and 2007.

SC asked for agreement or comments on the objectives as drafted in the report. The draft objectives were accepted with some amendments, and further suggestions.

10. Comments on draft JLA Annual Report

The SG members were asked to comment on the report and for any further suggestions and feedback relating to its content to be sent to IC by the end of the week. IC will amend the report in light of feedback received. The final report will be signed off by SC.

Action: IC, SC & All

11. Summing up and clarification of action points agreed.

It was agreed that the members would consider whether they would be prepared to continue contributing to the Steering Group beyond the summer. It was also agreed that there is a need to strengthen clinician participation; this will be discussed further at the next two meetings.

Action: All

12. Dates for future meetings of the JLA Steering Group

It was agreed that there would be two more meetings of the current Steering Group. PA would email members to get dates for April/May and July.

Action: PA

13. Future meeting dates:

2 May 2006 1-4pm, RSM, London

12 July 2006 1-4pm, RSM, London