

## Minutes of the 3rd Meeting of the Steering Group of the James Lind Alliance, Royal Society of Medicine, 13 September 2005

### 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
Ms Jenny Hirst	Chair, Insulin Dependent Diabetes Trust
Prof Stephen Holgate	Professor Respiratory Medicine, Southampton General Hospital
Dr Marcia Kelson	Associate Director, Patient and Public Involvement Programme, NICE
Ms Veronique Moodie	Deans Office, Royal Society of Medicine
Mr Nick Partridge	Chair, INVOLVE
Dr Sophie Petit-Zeman	Director of Public Dialogue, Association of Medical Research Charities
Dr Peter Sneddon	Head of Programmes, R&D Division, Department of Health
Mr David Tovey	Editor, <i>Clinical Evidence</i> , BMJ
Ms Maxine Whitton	Member, Cochrane Skin Group

### Apologies:

Prof Glyn Elwyn	Chair, Department of Primary Care, Cardiff University
Dr Anthony Harrison	Senior Fellow, King's Fund
Dr Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Dr John Scadding	Associate Dean, Royal Society of Medicine
Prof Charles Warlow	Neurologist, Western General Hospital NHS Trust, Edinburgh
Dr Chris Watkins	Trials Manager, Medical Research Council

#### 1. Welcome and introduction from the chair

Sally Crowe welcomed members to the third meeting of the Steering Group of the James Lind Alliance (JLA), especially to David Tovey, who has replaced Fiona Godlee from the BMJ Group. SC outlined the objectives of the meeting and highlighted the JLA's progress since the last meeting, noting that with each step of progress new challenges have emerged.

#### 2. Minutes of 24 May 2005

Accepted, with a couple of minor corrections.

Update on Item 6: The government has now published its response to the House of Commons Health Committee's report on the influence of the Pharmaceutical Industry. IC suggested that members of the JLA Steering Group (SG) should look for opportunities to support those of the Committee's recommendations that coincide with JLA objectives.

#### 3. Matters arising

SC informed the SG of the 'Work in Progress' document which the Development Group uses to track and summarise actions of the SG between meetings. This document is available to any members of the SG who wish to see it.

SH stressed the importance of addressing questions relating to the effects of complementary medicine. IC noted that questions about these will undoubtedly come to be included in the Database of Uncertainties about the Effects of Treatments (DUETs).

#### 4. Identifying areas of Uncertainty

MF gave an update of the progress of DUETs, and a presentation demonstrating the

database. He is currently concentrating on 3 topic areas; asthma, epilepsy and schizophrenia. There is still a lot of work to do, and there is currently no capacity to launch extensions beyond these three areas.

In discussion it was made clear that the role of DUETs was to identify shared interests among clinicians and patients and to show where current research is not addressing these sufficiently. MF is currently discussing with Asthma UK in relation to a pilot web-based patient survey.

Overall the feedback from the group for the DUETs project was very positive. The URL for the database is: <http://www.duets.nhs.uk>, MF is happy to receive additional feedback.

NP will supply HIV patient/clinical questions for DUETs. MK will supply questions from clinical groups for DUETs.

**Action: NP & MK**

## 5. Prioritising areas of Uncertainty

### ▪ *Asthma UK and the British Thoracic Society*

LF tabled and discussed a paper summarizing progress in developing the Working Partnership (WP) between Asthma UK and BTS, highlighting that 2 major meetings had taken place and that a meeting to plan next year's priority setting meeting was scheduled for December at the BTS Clinical Conference. Members of the Development Group will support and attend this meeting.

There was discussion about the level and breadth of patients' involvement should be at these meetings, and how to define who is best qualified/skilled to represent patients' interests, given the complexity of different patient experiences. It cannot be assumed that patient organisations keep in contact with a wide range of their patient members. It was agreed that: 'representatives' need to be able to raise the right issues, and that the JLA needs to be clear about how patient organisations and clinician organisations consult their respective constituencies. The JLA needs to develop a set of questions about exploring how organisations forming JLA WPs ensure that they are in a position to present "a broad range of perspectives". SC & LF will draft a list of questions and send to the SG for comment.

**Action: SC & LF**

### ▪ *Epilepsy*

LF gave a progress report on behalf of JS & CWar. JS & CWar contacted four epilepsy clinicians to inform them of the JLA and to find out if they would be interested in developing a JLA WP in epilepsy. They have received positive responses from Philip Smith and David Chadwick. CWar attended the Association of British Neurologists (ABN) meeting on the 7-9 September and will feedback to JS. LF will contact the Joint Epilepsy Council (JEC), which is an umbrella organisation for epilepsy patient organisations. SP suggested that it would be worth contacting the Brain Foundation, and she will send the relevant details to LF.

**Action: JS/CWar, LF & SP**

### ▪ *HIV*

NP has identified 3 clinician organisations, which may be interested in taking this initiative forward - the British Association for Sexual Health and HIV (BASHH), the British HIV Association (BHIVA), and Providers of AIDS Care and Treatment (PACT). NP proposes to write to each group individually and wait for their response. He will discuss with PA if the letter to come from him or the JLA.

NP also highlighted a potential issue when an umbrella group for a disease area doesn't exist i.e. the challenges of work with and across individual charities and voluntary groups competing for funding and commissioned work.

**Action: NP**

▪ ***Expressions of interest***

IC informed the group of the current JLA Affiliates, referring in particular to growing expressions of interest from patients and clinicians interested in skin disease. He mentioned that he had tried to find out from Noreen Caine and Janet Darbyshire whether the recently established UK Clinical Research Network, which Janet co-directs, would encourage JLA principles and processes for priority setting. Brief discussions with Janet Darbyshire had left him with the impression that the new networks will model their prioritization processes on those used by the Clinical Studies Groups in the National Cancer Research Network, but Janet Darbyshire had indicated that she is open to further discussion about this.

IC reported on the encouraging meeting on 31 August that he and MF had had in Wales with people involved in the proposed National Research Networks for Mental Health and Respiratory Disease there. Colin Gelder is the lead clinician for the latter and is keen to work with DUETs and the JLA. Although he was until recently chair of the BTS research committee, he was not previously aware of BTS's involvement in efforts to establish a JLA WP in asthma. IC has sent Colin Gelder LF's account of this work, and SC will make further contact with him.

**Action: SC, SH**

The issue of evaluation of the JLA process was raised, because it was clear that patients and clinicians should be happy with the JLA process and its results. The JLA will respond to organisations that think the JLA can provide an appropriate structure for what they are trying to achieve. After discussion it was agreed that the JLA would go ahead with the 3 pilot schemes currently envisaged – in asthma, epilepsy and HIV/AIDS.

**Action: SH, CWar, JS, NP**

**6. JLA information and publicity**

SP spoke about the JLA at a recent AMRC meeting she attended (also 20-30 charity Chief Execs in attendance) and was pleased to report genuine interest in the activities of the JLA. SP also posed the question of whether the JLA process could be used as a model and franchised to others. IC said that he thought that a working model was needed before deciding whether it should be rolled out.

The JLA leaflet, introduction and guidelines documents are ready and the mail out inviting affiliation is planned for 20 September. MK has distributed the JLA leaflet electronically to patient organisations on the NICE database. INVOLVE has offered to distribute 2,700 leaflets with its newsletter. The North West users Research Advisory Group will distribute 100+ leaflets locally. The Commission for Patient and Public Involvement in Health will inform their board and possibly distribute leaflets to their 400 Patient & Public Forums. The website has been updated so that people/organisations can join the mailing list and affiliate on-line.

LF, JS & MF will give presentations at the JLA session at the NICE Clinical Excellence Conference on 7 December. LF asked the SG what the key message should be. The discussion that followed highlighted the following points:

- The need to be honest about the obstacles and the experience gained from the Asthma WP.
- The emphasis of the presentation is to support as well as challenge the working partners.
- Highlight what has proved to be a success

IC is assembling papers showing mismatches between the questions about treatment asked by patients and clinicians and those being addressed by researchers. He plans that these should be made available on the JLA website.

## 7. Objectives and format for JLA Annual meeting, 3 December 2005

The SG members were asked to comment on the draft agenda for the meeting and for suggestions on its aims and format. SC asked the group to let her know if any of them would like to contribute. After discussion the following suggestions were made:

- The aim is to recruit JLA affiliates
- To engage patients and clinicians
- To address problems encountered so far
- Panel sessions
- Need to end on a positive note

SC thanked the RSM for providing the venue free of charge, (and JS for being the JLA 'champion' within the RSM), and the MRC (through CW and Elizabeth Mitchell) for providing some funding for the event.

The Development Group will reformat the agenda, taking into account the points raised.

**Action: JLA Dev Group & SG members**

SC urged members to ensure the date was in their diaries and to attend the annual meeting.

**Action: SG & PA**

## 8. Response to invitation to comment on 'Better Research for Better Health'

IC will submit a personal response to the consultation document. IC also has a draft copy of the response from AH, Kings Fund. It was agreed that it would be useful to send a response from the SG on behalf of the JLA. It was suggested that the response needed to identify areas that overlap with the JLA objectives, and to give a strong positive feedback on proposals that are consistent with the JLA objectives. IC will send a copy of the full report and the draft copy of the Kings Fund response to all the SG members. All feedback to be sent to SC who will coordinate the collective response.

**Action: IC/SC & All**

## 9. Any Other Business

It was agreed that the SG terms of reference document would be amended to include co-optation of new members.

**Action: SC**

SC asked for a verbal response from SG members (from those who had not yet responded) on whether they would continue on the SG until summer 2006. PA will chase up members who were not present.

**Action: PA**

IC drew attention to the GMC consultation on the redrafted text for the 'Good Medical Practice' booklet. Although acknowledgement of uncertainty is mentioned, there is no indication of what duties doctors have when confronted with uncertainties. IC will copy his response to other members of the SG, who may wish to draw attention to this point in other responses to the consultation.

**Action: IC & SG**

MK enquired about contacts between the JLA and DIPEX. IC reported that he had met twice with Ann McPherson and Sue Ziebland, who are both supportive of the JLA's objectives. DIPEX is a potential source of unanswered questions.

IC asked members of the SG for indications of what they wanted the JLA initiative to become. He noted that current funding for the JLA Secretariat ends on 31 December 2006. It was agreed that this should be a major agenda item for discussion at the January meeting of the SG.

**Action: SG**

## **10. Summing up and clarification of action points agreed.**

SC summed the themes of the discussion as follows:

- Progress is slow but steady! DUETs is developing well and the concept appears to have wide appeal. Working Partnerships continue to challenge all parties, but are worth the effort!
- The need for specific patient-centred and clinician-centred questions about treatments for each element of DUETs. This may prove challenging, but it is a fundamental requirement of the JLA process.
- A range of clinical/patient experience and perspectives in planning groups and prioritisation meetings (patient and clinicians are not homogenous groups).
- When sorting the evidence – think about the SKILLS required from both groups, for example, critiquing the quality of systematic reviews. This will help to avoid distorted clinical messages/questions.
- A sense of scale to the preparatory work for partners to assess resource requirements.
- Develop a list of questions that probe/assess the clinical/patient groups' capacity and enthusiasm for consulting/gathering views.
- The JLA WP process offers an alternative to the narrowing down of treatment options – reducing choice for clinicians and patients, as described by one SG member.

## **11. Dates for future meetings of the JLA Steering Group**

It was agreed that the frequency of the meetings would be same but that future meetings would only need to be a half-day. It was suggested that in-between meetings the SG could be kept updated via email and the website. The next meeting will be in January 2006; PA will contact members to find a suitable date.

**Action: PA**

## **12. Future meetings of the James Lind alliance; dates and venues**

JLA Annual Meeting – Saturday, 3 December 2005, RSM, London

Presentation of JLA's progress – 7 December 2005, NICE conference, ICC Birmingham

JLA Steering Group Meeting – 19 January 2005, RSM, London