

Minutes of the 2nd Meeting of the Steering Group of the James Lind Alliance, Royal Society of Medicine, 24th May 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
Mark Fenton	Editor, DUETs (Database of Uncertainties about the Effects of Treatments)
Mr Lester Firkins	Business consultant, Medical Research Council
Dr Fiona Godlee	Editor, <i>British Medical Journal</i>
Dr Anthony Harrison	Senior Fellow, Kings 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
Prof Charles Warlow	Neurologist, Western General Hospital NHS Trust, Edinburgh
Dr Chris Watkins	Trials Manager, Medical Research Council
Ms Maxine Whitton	Member, Cochrane Skin Group

Apologies:

Prof Stephen Holgate	Professor Respiratory Medicine, Southampton General Hospital
Prof Glyn Elwyn	Chair, Department of Primary Care, Cardiff University

1. Welcome and introduction from the chair

Sally Crowe welcomed members to the second meeting of the James Lind Alliance (JLA) Steering Group, and outlined the objectives of the meeting, which was to review progress and outline future plans for the JLA.

2. Introductions by members of the group

3. Minutes of the first meeting, 25 January 2005

Accepted, with correction to the spelling of 'Viteligo'.

4. Matters arising

No matters arising.

5. Changes following the first meeting to the JLA guidance documents

IC summarised the changes to the guidance documents in response to suggestions from members of the Steering Group. After receiving feedback from various additional sources, IC suggested that further revision of the documents was needed, in particular to introduce, in a more logical order, the challenges implied in addressing the JLA's objectives. After discussion, the following suggestions were agreed for the 'Description and Guidelines' document:

- Reorder and revise content. **Action: IC**
- Rename the 'JLA meetings' 'Priority setting meetings'. **Action: IC**
- Draft an abstract. **Action: SP**
- Develop a flow chart of the different stages leading to JLA Working Partnerships and priority setting. **Action: LF**
- Name the funders of the Secretariat. **Action: IC**

It was agreed that the 'Guidelines for meetings' document, would be redrafted to take account of experience with the asthma orientation meetings. **Action: SC & JS**

MK noted that it was important not to aim for perfection, and that it is more important to modify the guidance in the light of experience of the emerging Working Partnerships.

6. Discussion of comments received at the JLA Secretariat

SC gave a summary of a compilation of comments sent to the Secretariat following the first meeting of the Steering Group. These included:

- Spelling out the different kinds of uncertainties about the effects of treatments, making clear which the JLA would be addressing (there was no consensus on this)
- Linking to the House of Commons Health Committee's report on the Influence of the Pharmaceutical Industry
- Making other links from the JLA website, to inform the wider debate on uncertainty
- Keeping a clear focus on the agreed goals of the JLA
- Focusing on a developing process, and documenting the changes that occur
- Keeping the DH up to date with progress, especially where it related to the national clinical research networks

SO will provide the Secretariat with details of the evidence base supporting the objectives of the JLA.

Action: SO

AH will inform the Secretariat of items that may be of importance to the group and could be included as background material for the JLA website

Action: AH

SC will write to Sally Davies, DH, updating her on the progress of the JLA, copying Peter Sneddon in.

Action: SC

7. Formation of the JLA Development Group

SC outlined the rationale for creating the JLA Development Group. PA will post the minutes of each meeting of the Development Group on the JLA website, and notify members of the Steering Group by email of the URL, when this is done.

Action: PA

8. JLA Working Partnerships

a. Asthma UK and the British Thoracic Society

LF gave a presentation on progress so far. Two planning meetings have been held with a further one scheduled for September 2005 and the full JLA priority setting event in March 2006.

Lessons learnt from this "pilot" are;

- The process will take a long time if ownership and accountability are to be true and robust
- Closeness to patients wishes and opinions cannot always be assumed at the outset
- Partners may need skills training as the process exposes issues
- The JLA solution is needed and fills a void
- It will be hard work for everyone

b. Epilepsy and other neurological conditions

JS and CW have spoken to various people, including David Chadwick and Philip Smith, about the possibility of JLA Working Partnerships for epilepsy and other neurological conditions. There is a need to urgently tap into the alliance of epilepsy groups and/or the neurological alliance. JS will contact them again to find out if this is a possibility. MK will provide the address of epilepsy charities

and pass it on to SP who will check to see if there are any more before notifying the JLA Secretariat. It was suggested that Parkinson's disease may be a suitable condition for a Working Partnership, as the organisations already have the skills in place and communicate effectively with patients. SP will find out the details of relevant patient-led charities. Members agreed that it would be important to press ahead with exploring the possibility of Working Partnerships in one or more of these areas a.s.a.p, progress in this area to be reviewed at the July Development Group meeting

Action: JS, CW, MK & SP

c. Possible work with the new national Clinical Research Networks

IC referred to NP's suggestion last year that the JLA might wish to consider interacting with the Clinical Research Networks being established under the aegis of the UK Clinical Research Collaboration. At the time, a decision had been taken to concentrate on responding to Stephen Holgate's and Philippa Major's enthusiasm for concentrating on asthma. Because progress on asthma has been slower than anticipated, IC has discussed briefly with Sally Davies, Noreen Caine, Liam O'Toole and Janet Darbyshire whether DUETs and the JLA might usefully contribute to the identification and prioritisation of research questions for the new Clinical Research Networks, and they had agreed that this would be worth exploring. It was agreed that NP and IC should now actively pursue this.

Action: NP and IC

NP suggested that HIV might be a possible focus for a Working Partnership. The patient and clinician organisations have good relationships and have worked on research priorities before. He will speak to Janet Darbyshire and others to find out if the JLA would be welcomed.

Action: NP

CW thought that mental health would be a good possibility as the MRC had already identified this as a priority area, and the Wellcome Trust, AMRC and mental health charities are looking at ways of moving ahead to begin some dialogue. MF also has experience in mental health relevant to DUETs. Mental health is also another of the more well developed Clinical Research Networks. SP, MF and IC will take this forward and feed back to the group at the next SG meeting.

Action: SP, MF and IC

The group discussed the criteria that might indicate which patient and professional groups might 'fast track' the process envisaged by the JLA, and what might be used as indicators of success of Working Partnerships. Those suggested included:

- Are they membership organisations?
- Do they have a track record in consulting their members?
- Do they have a branch network?
- Do they have awareness of/are they proactive in research issues?
- Is there an alliance of related organisations?

Whilst there was no agreement to formalise this approach, should the alliance continue to struggle with recruitment of working partnerships this more proactive 'vetting' approach could be introduced in the autumn of 2005.

FG suggested that journals could be a useful way to promote the JLA and that it may be worth involving editors. It was noted that, although it was important not to raise expectations of the JLA prematurely, the BMJ had already proposed to publish an editorial on the need for greater clarity in recommendations for further research (in clinical guidelines, etc.), and the BMJ had invited the DUETs Working Group which had been

meeting to agree a checklist for research recommendations to submit an accompanying article about its work.

Action: FG

9. Database of Uncertainties of the Effects of Treatments (DUETs)

MF gave a presentation on the progress of DUETs so far. The group were asked to suggest sources of questions about the effects of treatments in addition to those that had already been identified. MF will follow up with an email listing these, and inviting additional suggestions.

Action: MF

10. Assessing applications for JLA Working Partnerships and Affiliates, including declaration of interests

JS explained that the JLA Development Group has taken on from the former 'Membership Advisory Group' the responsibility for assessing applications for JLA Affiliation and Working Partnerships.

JS asked for feedback on the draft JLA 'declaration of interests' form. CW will send JS a copy of the form used by the MRC so that a further draft can be considered. When this was ready, each member of the Steering Group would be sent a copy and asked to complete and return it to the Secretariat.

Action: CW (MRC), JS & ALL

All members of the Steering Group were asked to affiliate formally to the JLA, either as individuals, or through organisations (such as the MRC), or both. PA will send an email reminder to members to do this.

Action: PA and group members

11. Publicity inviting Affiliation

There was discussion about the best way to publicise the JLA, and to invite individuals and organisations to affiliate. It was agreed that a mass mailing would be done once the new JLA leaflet has been drawn up. Articles and documents relevant to the JLA would be included in the mailing, with the reasons for inviting affiliation made clear in the covering letter. PA would investigate the possibility of individuals/organisations applying for affiliation through the website.

Action: PA & Development Group

Once Affiliates had been signed up, ways of retaining their interest and keeping them informed would be needed. It was suggested that a newsletter could be sent at regular intervals by email or post. The Development Group will take this forward, with input from the Steering Group.

Action: Development Group

12. JLA leaflet, website (including new content), and talks given by group members

Members were invited to suggest what information should be contained in a JLA leaflet and for comments on its style. A wide range of ideas were produced which IC will use to draw up a draft document, taking into consideration the feedback from the group, the changes to the guidance materials and to include the following:

- Abstract: **Action: SP**
- Flowchart: **Action: LF**

Action: IC

PA asked for feedback on the new version of the JLA website, she will send out a reminder to do this in July.

Action: ALL

Members of the group were asked to let PA know if (and if so, where) they had given presentations referring to the JLA. Some PowerPoint slides are available from the Secretariat, if required.

Action: ALL

13. Outline plans for Annual Meeting of the JLA, and for the Steering Group

The Annual Meeting of the JLA will be on Saturday, 3 December 2005 at the RSM. The content of this meeting will be discussed at the next SG Meeting. SC & LF will find out from people involved in developing the asthma Working Partnership how they would like to contribute to the annual meeting. CW will find out whether MRC Corporate Communications has a budget to support the annual meeting of the JLA.

Action: SC, LF, CW (MRC)

LF & JS will present an update of the JLA's progress at the NICE conference on the 7 December.

Action: LF & JS

SC will approach members of the steering group in July/August individually to ask whether they would be prepared to serve for a further year, as this would seem to be a realistic time frame over which it is hoped that the first Working Partnerships will have emerged.

Action: SC

14. Summing up and clarification of action points agreed

SC thanked members of the Steering Group for a productive second meeting, which had covered a lot of ground, and asked that they check the minutes carefully as there were many action points arising from the day's discussions and decisions. PA and the development group will ask for an update from group members who have specific actions in the **first week in August**

15. Dates for future meetings of the JLA Steering Group

It was agreed that, if possible, the next meeting of the Steering Group should be in September 2005. PA will contact members of the group to find a suitable date.

Action: PA

16. Future meetings of the James Lind alliance; dates and venues

JLA Steering group meeting – 13 September 2005, 11am to 4pm, RSM, London

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

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