

Minutes of the 1st Meeting of the Shadow Steering Group of the James Lind Alliance At the Royal Society of Medicine 25th January 2005

Participants:

Ms Patricia Atkinson	James Lind Alliance, Secretariat
Sir Iain Chalmers	James Lind Library (JLL)
Mrs Sally Crowe (Chair)	Director, Crowe Associates
Prof Glyn Elwyn	Chair, Primary Care, Cardiff University
Mr Lester Firkins	Business consultant, Medical Research Council
Dr Anthony Harrison	Senior Fellow, Kings Fund
Dr Marcia Kelson	Director, Patient Involvement Unit, NICE
Ms Philipa Major	Assistant Director, Research, Asthma UK (part present)
Mr Nick Partridge	Chair, INVOLVE (part present)
Dr Sophie Petit-Zeman	Director of Public Dialogue, Association of Medical Research Charities
Dr John Scadding	Associate Dean, Royal Society of Medicine
Prof Charles Warlow	Neurologist, Western General Hospital NHS Trust (part present)
Dr Chris Watkins	Trials Manager, Medical Research Council

Apologies:

Ms Sarah Buckland	Director, INVOLVE Support Unit
Dr Fiona Godlee	Publishing Director, BMJ Knowledge
Ms Jenny Hirst	Insulin Dependent Diabetes Trust
Prof Stephen Holgate	Southampton General Hospital
Dr Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Ms Maxine Whitton	Vitiligo Society

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

Sally Crowe welcomed members to the first meeting of the James Lind Alliance (JLA) Shadow Steering Group, and described the overall objective of the Alliance. The co convening group, which had been 'incubating' the JLA concept since April 2004, was now handing over responsibility for guiding further development of the JLA to the shadow steering group. The co-convenors were looking forward to the input from the array of shadow steering group members with a wide range of experience who had agreed to guide the JLA's work strategically during 2005.

2. **What interests do members of the Steering Group have in the James Lind Alliance, and what skills/experience can they offer?**

- Keen to build on previous related activities engaging the public e.g. RSM 'Medicine and Me' meetings
- Enthusiasm for the JLA idea and having a clear goal to strive for, bringing some good business practice to JLA work
- Support for public engagement
- Interest in and experience of the role of public interface in developing research agendas
- Experience of working with alliances and partnerships e.g. Neurological Alliance
- Patient organisation involvement techniques; sharing NICE's experience of Guidelines and Health Technology Appraisal development (avoiding reinventing the wheel)

- Evolution of shared decision making, communicating risk, and the primary care context
- Experience of the history of research agendas; “clinician/public” getting the right medicines. Organisation can offer a platform for and advice for the JLA
- Frustration in communicating the ‘fair test’ concept, and with media sensationalization of clinical trials. JLA offers a forum for patients/public and clinicians to identify and address informed uncertainty
- Experience in techniques of patient/public engagement; critical appraisal skills for understanding research and facilitation of groups
- Enthusiasm, secretariat support

3. **Overview of progress so far – presentations from members of the 2004 co-convening group**

SC introduced the terms of reference document and asked for comments. There was a general consensus that the steering group meetings would need to be more frequent initially to keep up the momentum, and that the next meeting should be scheduled within the next 4 or 5 months. The terms of reference were taken as read with an amendment to the frequency of the meetings. Some members are exploring with their respective organisations, whether they represent their employers or are ‘individual’ members; this needs to be clear in the documentation. Most of these organisations would be natural affiliates of the JLA.

Action: SC

It was also suggested that members of the steering group should complete a declaration of interest form. SC and JS will review the form to increase its clarity and send it to the members of the steering group via email.

Action: JS & SC

Guidance for membership document: JS gave the group an overview of the ‘Guidance for membership’ document and asked for feedback. After some discussion it was agreed that the objectives, as currently drafted, did not convey sufficiently explicitly what the JLA was trying to achieve, and that progress towards achieving objectives needed to be measurable. It was agreed that the objectives would need to be reworded, and helpful suggestions were made. SC will look at these, redraft the objectives and send them out to the group for feedback.

Feedback on objectives:

- Objectives should be SMART (Specific, Measurable, Achievable, Resourced/Relevant, and Timed)
- For each objective there should be a measure of success
- A measure of success could be who are attracted as affiliates, what they can offer and how they can support the JLA
- Other measures of success could be: action plans, planning meetings, the way research questions emerge
- It is important to be realistic about what the Alliance can be expected to achieve in the short and longer term
- There is a need for clarity about when and how the pharmaceutical and other industries get involved
- Helpful to think about objectives in terms of influence and more operational
- JLA should take responsibility for developing the process for arriving at shared research agendas

Action: SC & PA

Further feedback on the guidance documents:

- It was agreed that the title 'JLA Members' be changed to 'JLA Working Partnerships'
- It was agreed that potential JLA Working Partnerships need to state the extent to which they have approached other groups
- Most organisations will have also done some work on research prioritisation and this needs to be included into the discussion at meetings
- It was suggested that it would be a good idea to involve the HTA in planning meetings, they have indicated in their Affiliate application that they are interested in making this contribution
- It was agreed that reports and action plans from JLA meetings would be posted on the JLA website. Concerns were expressed that JLA Working Partnerships might deliberately or unintentionally exclude other important clinical or patient groups in the consensus development. There needs to be an explicit effort to discuss participants at planning meetings
- Conversely there may be clinical/therapeutic areas that attract a lot of attention and issues of managing expectations may need to be discussed at planning meetings
- The group also agreed to concentrate on a small scale/pilot approach, aiming to convene two JLA Working Partnerships to get the process right and to learn what works
- The current guidance describes the explicit exclusion of commercial interests in JLA activity. It was agreed that the wording was ambiguous and what is important is that industry is not included in the process of developing shared research priorities.
- If, at the end of the JLA process, evaluation of a commercial product has been deemed a priority, then engagement with industry may be needed, but this could still be at arm's length, with all aspects of the research being conducted independently, within a non-commercial framework
- These discussions helped to clarify where the JLA's work begins and ends. The JLA process achieves its objectives at the point at which agreement between patients and clinicians has been reached on their shared therapeutic research priorities.

The meetings document will be amended to reflect these points.

Action: SC & PA

There was a discussion about JLA Affiliates.

- How do we link Affiliates into the process to avoid them being sleeping partners?
- How do Affiliates contribute to the JLA objectives?
- How can we harness the expertise of Affiliates effectively?
- How do we make sure registration with the JLA adds value for Affiliates?
- Could registration as an Affiliate and involvement in a JLA Working Partnership run in parallel?
- Can individuals register as Affiliates?

Action points included:

- Arrange for Affiliates to have copies of minutes/steer them to the website
- Push the 'affiliation is free' message
- It was agreed to have targeted publicity for affiliate membership at this stage
- Ensure next publicity mailing has examples of the JLA Working Partnerships

The steering group seemed clear about what they wanted from affiliate members

- They need to state what they can give

- They can provide a groundswell of support
- Further/help in planning JLA meetings
- Pick up research consensus for funding
- To encourage a strategic/consistent response to issues in research agendas
- Membership advisory group to filter applications

Action: SC & PA

Publicity:

- A record will be kept of publicity undertaken by members of the steering group.
- The secretariat will provide material for publicity. Copies of articles relevant to the JLA will be sent to members of the steering group.

There was discussion about the timing of a large publicity mail out to patient and clinician organizations. It was clearly inadvisable to do this before the Guideline documents and redesign of the website had been finalised, and desirable to do it when there was some 'success to share'.

Website:

- The website would be updated once the new objectives had been agreed.
- FAQ's derived from the NICE conference feedback to be posted on the website

Expressions of interest from groups: In addition to asthma, other allergic diseases, and some neurological conditions, expressions of interest in the possibility of forming JLA Working Partnerships had been indicated by musculoskeletal disease, trauma, skin disease, breast cancer, and ear, nose and throat disorders.

4. The role of DUETs (Database of Uncertainties about the Effects of Treatments) in the James Lind Alliance and information about ongoing trials–

Unanswered questions about the effects of treatments can be identified using a number of sources. Of particular importance are those emerging from enquiries directed by patients and clinicians to question answering services, but important unanswered questions also emerge when preparing systematic reviews and clinical guidelines. The Database of Uncertainties about the Effects of Treatments (DUETs) is being established to capture and codify these questions, as a service to JLA Working Partnerships and as a resource to those planning JLA meetings, but to others as well. The database will be open access through the National electronic Library for Health (www.nelh.nhs.uk), and will contain links to information about relevant ongoing clinical trials.

5. Discussion concerning the issues highlighted in the report of the NICE conference and the first annual meeting of the JLA

SC fed back in broad terms from this important first public airing of the JLA. There was much feedback on many aspects of the JLA, most of which had made its way onto the agenda for the steering group today. Outstanding issues included:

The James Lind Alliance name and image

There was a discussion on whether the current 3 logo's for the JLA should be kept. There was also a debate on whether the JLA name should be changed. It was decided that it was too late to change the name and that the 3 logo's were representative of the partnerships that JLA is all about. It was decided that a clear concise strap line could address these concerns. There were various suggestions but the following strap line best represents the contributions from the group:

'Tackling treatment uncertainties – together'

The partnership model – will it work?

It was recognised that there are many possible types of JLA Working Partnership, and the JLA would have to work with the 'best fit' for particular circumstances. It should not attempt to stick with a pair of organisations if involving more than two seemed sensible

In order to facilitate effective partnerships part of the JLA process should be encouraging the partners to think about and discuss:

- How do they currently work together?
- Have they defined research priorities together/separately?
- The importance of the health problem in the respective organisations. For example, to Asthma UK asthma is everything, but to the British Thoracic Society it is one of many important health problems, and this will have a bearing on how they work together
- Has each organisation got a JLA champion? If not they need one!
- When/how should people living with the health problem (the core constituents) become involved?
- How will research priorities identified through JLA process compete for funding with research priorities identified in other ways?
- What is the 'added value' to JLA Partnership organisations from involvement in the JLA. (for example, possible easier access to helpful groups)

6 **Summary of the action/development points agreed and summing up of the position so far:**

- We have improved the JLA objectives
- We have clarified the boundaries of what the JLA can achieve and how it interacts with industry
- We have improved the branding of the JLA with a new strap line.
- We have agreed to focus attention in 2005 on piloting the suggested approach/process, and learning from others doing similar work
- We have agreed to delay a large scale publicity drive to patient and clinician organizations until we have a better understanding of how the JLA Working Partnerships will function
- We have a clearer understanding of what Affiliates can offer the JLA and how we can get them involved
- Following feedback from Asthma UK, we have agreed that a three stage process - orientation, planning and consensus development - was a more realistic step by step process
- We have improved the guidance documents and removed ambiguities
- We have formed a powerful group that will help the JLA to achieve its objectives in 2005

7. **Any other business**

Presentation from Philippa Major, Asthma UK on the problems and issues they have been facing in an attempt to form a partnership and submit an application with the British Thoracic Society. Philippa raised the following question:

'What sorts of people need to make up the first planning group?'

The group agreed that a three stage process, starting with an orientation meeting to precede the planning meeting to agree working arrangements and resourcing etc.

British Thoracic Society Chief Executive

Office staff

Patients with asthma

The James Lind Alliance will supply an independent chair.

SC agreed to develop an outline agenda for the orientation meeting

JS will help Mark Hohenberg to prepare papers about the JLA Student Prize for presentation at the annual meeting of the RSM Student Section on 22 April.

8. Future meetings of the James Lind Alliance; dates and venues

JLA Asthma orientation meeting - 7th March 2005, 2pm-4: 30pm at the Royal Society of Medicine

JLA Steering group meeting – 24 May 2005, 11am to 4pm at the Royal Society of Medicine