

Minutes of the 6th Meeting of the Steering Group of the James Lind Alliance, Royal Society of Medicine, 12 July 2006

Participants:

Ms Patricia Atkinson	Administrator, James Lind Alliance Secretariat
Sir Iain Chalmers	Editor, James Lind Library
Mrs Sally Crowe	Director, Crowe Associates
Prof Glyn Elwyn	Chair, Primary Care, Cardiff University
Mr Lester Firkins	Business consultant, Medical Research Council
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Prof Stephen Holgate	Physician, Southampton General Hospital
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 Research Programmers, Department of Health
Dr David Tovey	Editor, Clinical Evidence, BMJ

Apologies:

Dr Anthony Harrison	Senior Fellow, Kings Fund
Dr Marcia Kelson	Director, Patient involvement Unit for NICE
Dr Chris Watkins	Trials Manager, Medical Research Council
Prof Charles Warlow	Neurologist, Western General Hospital, Edinburgh
Ms Maxine Whitton	Member, Cochrane Skin Group

1. Welcome from the chair

SC welcomed members to the sixth meeting of the James Lind Alliance (JLA) Steering Group (SG).

2. Minutes of 2 May 2006

The minutes of the last meeting were accepted.

Matters arising:

Minutes 19 January 2006, Item 5 – ‘*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.*’ SC will follow up this action.

Minutes 19 January 2006, item 5 – ‘*MRC call for proposals on methodology research on the implications of research. SO interested in carrying out this piece of work.*’ SO reported to the group that the proposal was unsuccessful, but that she would be doing a piece of work with Jenny Gray to extend and improve the existing JLA bibliography, funded by the JLA. The work will consist of searching systematically for and classifying broadly, studies that compare patients’ research questions and treatment outcomes with those of researchers and highlighting the mismatches. The long term aim will be to investigate the methods used to find important questions. SO will contact the SG by email if she needs any assistance. SC will put SO in touch with Dr Kristie Haywood, Royal College of Nursing Institute, who is working on patient outcome.

Action: SO & SC

3. Working Partnerships update

Asthma – SC updated the group on the current progress of the Asthma Working Partnership (WP). SC reported that the WP was progressing well and that there is now a taxonomy of terms for the asthma data. A future teleconference will be convened with a small group which will include a respiratory nurse and other clinicians patients/people with asthma to finesse the indicative questions and look at the shared uncertainties. The group have agreed to use the adapted nominal group technique for the final priority-setting process.

SH informed the group that he is due to become president of the BTS and will champion what the JLA is trying to achieve and aim to get the public involved in the work of the BTS. SH mentioned that the following paper 'Priorities for Respiratory Research in the UK' put together by the BTS and the British Lung Foundation, will be made public in the next couple of weeks.

SH also mentioned a patient-centred meeting in Brussels entitled 'Change in Asthma management'. He wondered if a representative of the JLA would be available/willing to present at this meeting. The meeting will be attended by patients, clinicians, public and industry. SH to forward details of this meeting to SC & PA

Action: SH

IC asked SH for reflections on how the JLA might have done things differently. SH responded as follows:

1. SH explained that the BTS is a very narrow group, which consists of clinical doctors, nurses and some general practitioners, who are service orientated. BTS covers a variety of respiratory diseases, and is not representative of the spectrum of professionals who care for people with asthma.
2. AUK had had staff changes that interrupted the flow of setting up the JLA Asthma WP.
3. The JLA needed to identify in each organisation team who would be the lead.
4. The WP felt they were being told what to do. The process seemed to be formalised before the partnerships were fully engaged.
5. SH suggested that, in future, it would be important to base plans on more personal, rather than institutional, interactions.

IC noted that the idea of encouraging organisations (rather than just keen individuals) to work together was that it would be less easy for funders to ignore research priorities emerging with the 'institutional' endorsement implied using this approach. He asked whether others felt that this approach was misguided. SH said that the approach should not be abandoned, but that it was important to find the right people to work with within organisations. Perhaps making initial contact with presidents rather than with chief executives would lead to a broader view of who within their organisations were the appropriate people for the job.

SC said this was why it is important to continue to debrief with partnerships and highlight the pitfalls encountered along the way. LF has prepared a paper of questions for organisations to think about before attempting to form a WP, that has been informed by this process.

JS commented that individuals representing large organisations might feel that they needed to check within their organisation that they had authority to proceed at every stage of the process, causing delay. There were good examples of patients and clinicians working effectively together as individuals, not representing organisations, for example in rheumatoid arthritis research.

Epilepsy – LF reported that he had received a response from Sharon Harvey, General Secretary, Joint Epilepsy Council (JEC) in relation to the possibility of a WP in Epilepsy. Sharon informed LF that the JEC felt they were not in a position to take this forward due to possible lack of resources. They would like to keep their options open and to this end would like to speak to someone involved with the asthma WP to get a feel of what is required and the outcomes from their perspective.

Rheumatoid arthritis – LF is due to meet with John Kirwan and Enid Quest on the 21

August and will report back at the next meeting.

Incontinence – LF reported that the JLA has received an expression of interest from InContact re a possible WP in incontinence. LF has responded informing them of the procedure they need to follow before forming a WP. The interested parties have also raised the possibility of formally studying the JLA WP process. LF will report back any further developments.

SH suggested that it might be a good idea to get economic commitment from the WP's which in turn might provide more motivation. GE pointed out that it would be easier to go this route if the JLA had a successful WP under its belt.

4. Progress on the Database of Uncertainties about the Effects of Treatments (DUETs)

IC explained that the reason for uncoupling the development of DUETs from the development of JLA WPs was that the former could proceed usefully while the more challenging and inevitably slower process of developing JLA WPs proceeded. For example, the Welsh Office for Research and Development (WORD) has provided funding for a development officer for DUETs for 2 years to harvest questions in schizophrenia and epilepsy. Furthermore, recent discussions with Ray Armstrong and others associated with the Specialist Libraries within the National Library for Health, have welcome suggestion that future DUETs modules be developed under the aegis of the Specialist Libraries. Even though DUETs would not be solely linked to JLA WPs it would still be there for the use of the WPs.

5. Membership of the Steering Group

SC referred to the paper relating to the current and proposed Steering Group (SG) membership. Maxine Whitton is sadly standing down due to other commitments. SC thanked Maxine in her absence for her contributions to the work of the JLA. A card and voucher will be sent to Maxine as a small token of gratitude. It was pointed out that Mark Fenton was not actually a member of the SG and will only attend future meetings if appropriate, and that IC will update the SG on the progress of DUETs as needed.

Action: PA

It was agreed that Marianne Miles, Patient/Public Liaison Lead, UKCRN, Philippa Yeeles, Programme Manager for the UKCRC and Mark Welfare, Gastroenterologist/senior Lecturer Northumbria Healthcare NHS Trust should be invited to be part of the new SG. LF will contact Marianne and Philippa, and SC will contact Mark to discuss this. A formal letter will be sent inviting them to sit on the SG for the coming year.

Action: LF & SC

6. Changing the focus of the work of the JLA Steering Group

SC gave an overview of the paper relating to the change of focus of the agenda for the SG. The paper was initiated after receiving feedback from various members of the SG in response to the letter asking them if they wished to extend their JLA SG membership. It was decided that the WP work would not dominate the agenda. The revised agenda would address the wider issues of research priority setting and aim to engage the Affiliates by requesting their assistance in some of the objectives of the JLA work. SC asked the members what they thought of this proposed change of focus.

The overall consensus was that it was a good idea to have a more strategic agenda which would better utilise the knowledge and experience of the Steering Group members. JH agreed with the new focus and reminded the group that what the JLA had been through with the current WP was a very valuable experience. SH pointed out that it was still important that there was a small group available to support the WP's. The JLA Development Group will continue to address the day to day work of the JLA with steer from the SG.

IC informed the group that within his role of the James Lind Initiative he would continue to push the principles of the JLA, via articles and talks even though there were currently no

deliverables to show. PS reassured IC that within the remit of the funding from the DH and MRC there was not a need for concrete outcomes at this stage, and that maybe deliverables may manifest at a later stage.

SP explained that the AMRC had still not Affiliated to the JLA, due to fact that the charities wanted evidence that the model of the JLA works. JH highlighted that many charities were not even at the stage that they could consider being part of a partnership due to their lack of understanding of the basics needed for this venture. JH suggested the JLA could help charities understand the basics by developing an early stage of the model which could get the right people within the charities interested.

PS felt the statement 'How the JLA can influence the UK Clinical Research agenda' was too broad and should be made more clear. How are the JLA trying to influence funders? *(As a result of this comment and further discussion see objectives 6, 6.1, 6.2 & 6.3, below, which aim to address this statement)*

7. Chairing and Renaming the JLA Steering and Development Group

SC asked the group if they felt there was a need for a clinician as co-char. The consensus was that it would be less confusing with one chair and that everyone was more than happy with the job being done.

It was suggested and agreed that the SG and DG should be appropriately renamed as follows:

- SG = JLA Strategy and Development Group (SDG)
- DG = JLA Monitoring and Implementation Group (MIG)

(For the purpose of these minutes SG and DG will be used and the new naming convention will be put in place for future minutes and correspondence.)

8. Promoting the objectives of the JLA, via steering group membership and Affiliates

SC asked the group to consider the current JLA objectives for 2006/2007 as laid out in the 'changing the focus of the JLA SG' paper. After discussion the following was agreed (*in italics*), and the objectives are presented in a revised order:

JLA Objectives for 2006/2007	
1.	Explore with the Clinical Research Networks how research priorities are identified. <i>Important to deliver within the next year.</i> 1.2 JLA Survey of research funding organisations to assess the extent to which patients/the public/non-research clinicians are involved in setting research funding priorities, or JLA input to survey if already being organised by UKCRC/UKCRN
2.	Collaborate with other organisations in organising two symposia to discuss issues relevant to the JLA's objectives. <i>Important to deliver within the next year.</i> 2.1 JLA Initiative on transparency in sources and amounts of funding support for patients groups. SPZ is checking with AMRC on guidelines that are being developed (scheduled to be complete by end 2006/early 2007) and will circulate these to NP/JH/IC when ready with a view to developing a symposium with the guidelines being a key part of the discussion? IC suggest that the Affiliates be invited to contribute. Action SPZ (NP & JH).
3.	Explore whether some medical research charities/other funders can extend JLA methods. <i>(via Affiliates or other networks)</i> 3.1 Testing Treatments card. <i>Idea developed by IC & SPZ but will be carried forward by SPZ</i> Action: SPZ

	3.2 Ask Affiliates how they can contribute to the JLA Objectives. <i>Affiliates applications to be reviewed</i> Action: PA & IC
4.	Conclude the priority setting cycle of the JLA Asthma Working Partnership. <i>Operational work to be done by the DG</i>
5.	Establish two further JLA Working Partnerships. <i>Operational work to be done by the DG</i>
6	Adopt the lessons learned from the piloted working partnerships and other models. <i>Operational work to be done by the DG</i>
7.	Reviewed the resources needed to achieve successful partnerships <i>Operational work to be done by the DG</i> 7.1 JLA bibliography of patient/clinician/researcher matches/mismatches in research priorities/outcome measures. 7.2 JLA systematic review of material in the JLA bibliography. <i>Develop a protocol once the bibliography done</i>
8.	Establish a mechanism for rotating off the Steering Group members from summer 2006. <i>Done</i>
9.	Secured funding to support the continued development of the JLA from 2007 to 2010. <i>Currently in progress</i>

The objectives for 2006/2007 will be rewritten to reflect the discussion of the current and additional objectives/projects and circulated for the next meeting.

Action: JLA Dev Group

SPZ suggested that we invite the research charities to meet with the JLA SG to have an open and frank discussion to discuss what we are trying to do and the pitfalls encountered. This would form the basis of a meeting/paper.

SH raised the issue that participants in research were not always a true reflection of the population who have a particular condition/disease. IC asked the question how can we ensure research reflects reality, with involvement from the elderly and children? It was decided to hold a joint one day meeting with the JLA and *Clinical Evidence* to discuss this issue involving IC, SH, DT, GE and others.

Action: IC& DT

SC will send the 'UK Health Research Analysis' paper to the SG, as this describes the UKCRC work to map health research spend within the larger research institutions in the UK.

Action: SC

NP raised the issue of revisiting the current JLA material in light of what is now known with a view to updating them. This will be looked into at a later date.

9. Affiliates update and development

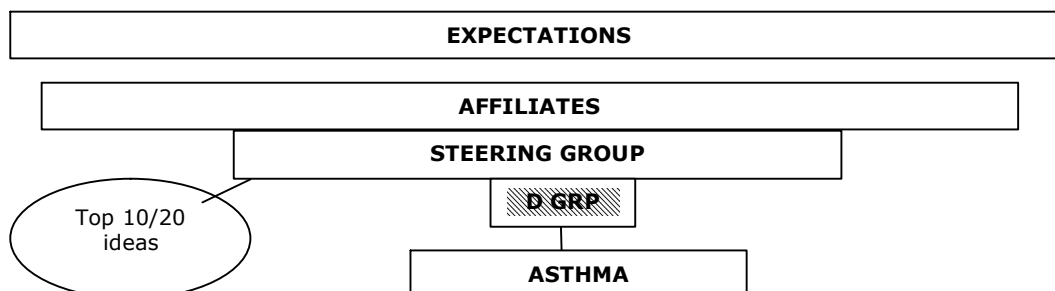
It was agreed that there is a need to have a real dialogue with the Affiliates. LF suggested that it would be a good idea to ask Affiliates how they would like to contribute to the objectives of the JLA, which would in turn empower and engage them.

It was noted that there were not many patient groups Affiliated to the JLA. GE suggested that many patient groups were not ready for what the JLA had to offer, and that the JLA needed to present a clear outline of the current status and what it is all about. He said the patient groups should be asked the following questions: Where they think they fit into the JLA process? What contribution would they like to make? Are they just supporters, what is their time frame? This would be a useful motivational tool. LF will produce a paper on the concepts of the JLA.

Action: LF

10. Future support for JLA Activities

LF explained to the group that the JLA Development group (DG) (currently consisting of 6 members, but would be going down to 4) was quite small and shouldered the weight and expectations of the Asthma WP, SG, Affiliates and others who supported the work of the JLA.



LF invited volunteers from the members of the SG to join the DG or to suggest ways in which the membership of the DG could be increased. GE suggested that perhaps the group could call on people with the appropriate skills for various projects as the need arose. (since this meeting GE and SPZ have volunteered to be members of the of the newly named 'JLA Monitoring and Implementation Group' (MIG).

The Dev Group currently meets monthly in Oxford, but could change to 6 weekly and meet in other venues like London or Cardiff as appropriate.

LF suggested that each SG member produce a list of 10 things they would like to see the JLA working on, highlighting the items that they could contribute to. PA to co-ordinate.

Action: Steering Group & PA

PS reiterated that the DH & MRC were happy to continue the support of the work of the JLI as they were happy with what was being done and in principle have agreed to continue funding beyond 2007.

11. Summing up and clarification of action points agreed

- This meeting had been more purposeful and lively, with more contributions from the SG members.
- Re-prioritised and added to the JLA objectives with discrete pieces of work to be taken forward by DG & SG members.
- Refocused the work of the group – more strategic and wide ranging, playing to the strengths of the group and the success so far of the JLA.

SC thanked everyone for coming.

12. Future meetings

Future meetings in other parts of the country were suggested. GE has offered Cardiff University and the James Lind Initiative has meeting room facilities available in Oxford.

PA will put out feelers for meeting dates and venues for the following months:

- October 2006
- February 2007
- June 2007