

**Minutes of the 7th Meeting of the Strategy and Development Group of the James Lind Alliance,
Royal Society of Medicine, 17 October 2006**

Participants:

Ms Patricia Atkinson	Administrator, James Lind Alliance Secretariat
Sir Iain Chalmers	Coordinator, James Lind Initiative
Mrs Sally Crowe	Director, Crowe Associates
Mr Lester Firkins	Business consultant, Medical Research Council
Dr Anthony Harrison	Senior Fellow, Kings Fund
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Dr Marcia Kelson	Director, Patient Involvement Unit, NICE
Dr Marianne Miles	Patient/Public Liaison Lead, UK Clinical Research Network
Mr Nick Partridge	Chair, INVOLVE
Dr Sophie Petit-Zeman	Director of Public Dialogue, Association of Medical Research Charities
Dr John Scadding	Dean, Royal Society of Medicine
Dr Peter Sneddon	Head of Research Programmes, Department of Health
Dr David Tovey	Editor, Clinical Evidence, BMJ
Dr Mark Welfare	Gastroenterologist/Senior Lecturer, Northumbria Healthcare NHS Trust
Ms Philippa Yeeles	Programme Manager, UK Clinical Research Collaboration

Apologies:

Prof Glyn Elwyn	Chair, Primary Care, Cardiff University
Prof Stephen Holgate	Physician, Southampton General Hospital
Dr Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Prof Charles Warlow	Neurologist, Western General Hospital, Edinburgh
Dr Chris Watkins	Trials Manager, Medical Research Council

1. Welcome from the chair

SC welcomed members and new members, Marianne Miles and Philippa Yeeles, to the seventh meeting of the James Lind Alliance (JLA) Strategy and Development Group (SDG).

2. Minutes of 12 July 2006

The minutes of the last meeting were accepted.

3. Working Partnerships update

Asthma – SC gave an overview of the distributed summary paper of the Asthma WP. SC hoped she would be able to report on the completion of the Asthma prioritisation process at the next SDG meeting in February 2007.

Epilepsy – JS reported that he had been in discussions with Tony Marson, Senior Lecturer in Neurology and Co-ordinating Editor, Cochrane Epilepsy Group (Affiliate of the JLA). Dr Marson has applied for a programme grant to the National Institute for Health Research to undertake work which he feels is of direct relevance to the JLA. He would like to collaborate with the JLA on this work, in which Epilepsy Action and the Mersey Region Epilepsy Association will also be involved. Mark Rees, Phil Smith and Margaret Jackson are three other epileptologists who are very interested in being part of this process. MK suggested that it would be a good idea to contact the NICE Epilepsy group. MK will pass on the relevant contact details to JS.

Action: MK

JS will convene a teleconference before Christmas which will be facilitated by himself and Charles Warlow. LF will lead on the Epilepsy project.

Action: JS

Incontinence – LF reported on his meeting with Brian Buckley, Chair of Incontact (patient side), Adrian Grant, Coordinating Editor of the Cochrane Incontinence Group (clinician

side), and two others. They are very keen to work with the JLA and have submitted a funded JLA Incontinence WP protocol, which includes DUETs. They have also established a MRC-funded PhD studentship based in the Health Services Research Unit at the University of Aberdeen, as they feel a JLA WP on incontinence presents a valuable opportunity to incorporate a qualitative evaluation of JLA methods. 2/3 years have been allocated for this project.

The PhD student would like to share her plans with the JLA at the next SDG meeting in February. LF will contact Jenny Versnel to find out if she would be willing to talk to her about AUK's involvement in the JLA WP process. LF asked the SDG for feedback on the proposals as outlined above

Action: SDG

It was suggested that this work could possibly be linked to incontinence in gastroenterological disorders, MW's field. LF will send all the information relating to this project to Mark Welfare for further discussion.

Action: LF

Rheumatoid arthritis – LF met in Bristol with John Kirwan, Consultant Rheumatologist, Enid Quest, patient research partner, Pamela Richards, patient, and Sarah Hewlett, Clinical Nurse Consultant. LF gave an overview of the project outline circulated by John Kirwan, and explained that he is looking for collaboration with the JLA and INVOLVE, but not to establish a JLA WP. The JLA Monitoring and Implementation Group is currently looking at the proposal and will contact INVOLVE to get their perspective.

Diabetes – JH has been in discussion with Ron Marsh from Scotland, about the possibility of a diabetes WP. JH noted that patients who join patient groups are not necessarily the typical patients. JH and Ron envisage the use of clinicians and clinics to draw in the true patient perspective.

MW suggested applying for funding to do local work with patient focus groups to see what it would take to set up a WP, mentioning that he hoped that the National Association for Colitis and Crohn's Disease might become involved in the incontinence work.

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

IC reported that, following meetings with those responsible for the specialist libraries in the National Library for Health, it had been decided that DUETs would be rolled out using the specialist library infrastructure. Mark Fenton had prepared a guide for those wishing to take on the development and maintenance of a DUETs module. This had been pre-circulated and any feedback on it from members of the JLA SDG would be welcome.

Action: All

AH mentioned he was working on a brochure with a view to interesting people in funding work relevant to the JLA's objectives. SPZ asked him to consider involving the AMRC in this.

5. JLA Objectives

There was discussion on some of the JLA Objectives, as follows:

1. Explore with the Clinical Research Networks how research priorities are identified

SC ensured that everyone was aware of the UKCRC Health Research report, which had been circulated prior to this meeting.

PY then gave an overview of her work with the UKCRC and explained that it is a partnership of organisations working together to improve clinical research in the UK. She said that one of her main focuses was on patient involvement, and that SPZ and IC were also involved in a UKCRC group considering this. PY highlighted the 4 strands of the PI Project as follows:

- 1) New web resource for patients and the public;
 - 2) Patient and public involvement in research contracts;
 - 3) Developing the evidence base about patient involvement;
 - 4) Developing standard criteria for assessing public involvement in applications to funders.
- There was some lively discussion about the future of clinical research in the UK and the especially the problems faced at 'ground level' in trusts.
 PY will send a copy of the progress report of the work of the UKCRC to the SDG when it is available.

Action: PY

MM gave an overview of her work with the UKCRN. She explained that the Network is working to develop and strengthen the NHS infrastructure to support best quality studies in the UK. MM's role is to support public involvement across the areas.

MM said that the work of the JLA was very timely, and suggested the use of the JLA model in the work of the UKCRN. IC said that the JLA could act as a 'ginger group' to challenge, and wanted to know of ways the JLA (either as a group, or as individuals) could help to promote the interests of patients within the UKCRN. MK suggested that NICE could also feed into this process, and that it would be a good idea to draw on some of the lessons already learned there.

SC tried to summarise the wide-ranging discussion in relation to this objective concerning priority setting and clinical research:

- Priority Setting is currently in sharp focus
- To gauge how it is currently being done is a huge task and we have started to address some of the issues
- The JLA can be part of the solution, by providing described (and eventually evaluated) priority setting methods, DUETs, a network of interested stakeholders
- We need to agree with UKCRC/UKCRN entry points to work with groups to test our methods
- The JLA can lobby for change via UKCRC Board

It was agreed that MIG members would meet with the UKCRC and UKCRN outside of this group to explore progress relations and actions

Action: MIG members especially SC and LF

2. Collaborate with other organisations in organising two symposia to discuss issues relevant to the JLA's objectives.

Proposal for a 1-day symposium co-convened by the JLA and *Clinical Evidence*, to discuss how to ensure research reflects the reality of everyday practice, an issue raised by SH at the previous meeting of the JLA SDG. IC reported that he and DT had discussed possibilities, and that they had decided to ask Richard Horton, Editor of the Lancet, to consider co-convening a meeting with the JLA to coincide with the launch of a Lancet book edited by Peter Rothwell about applying the results of results in the clinical care of individuals. A morning session could address issues raised by SH; an afternoon session the related issue covered in the book. IC will keep SH and other members of the JLA SDG informed of progress.

Action: IC

Other topics for meetings discussed included, transparency in funding of patient organisations /methods in priority setting/DUETs progress/Results of the Asthma WP

Action: MIG to discuss these in more detail and sketch out a programme for 2007

3. Explore whether some medical research charities/other funders can extend JLA methods. (via Affiliates or other networks)

IC, SC & LF have reviewed the JLA Affiliates to explore what and how they can contribute to the objectives of the JLA and how the JLA can better engage them. The following were some of the comments raised:

- Simply sending a JLA newsletter would not be enough

- Need to understand better why Affiliates had affiliated, and how they could help
- Need to be more professional in approach
- Possibly meet with Affiliates
- To be aware of potential funders
- There needed to be a systematic approach to assembling offers of help

The MIG needs the SDG's help and suggestions on how to improve the involvement of Affiliates. SC asked MK if NICE used databases that would be suitable to the needs of the JLA. MK will find out. SPZ suggested applying for funding from the BIG Lottery Fund to establish a database, which would make this task more efficient.

Action: MIG to lead with help from all of group

IC suggested that the JLA might establish an email alert list to draw attention of Affiliates and others to articles, meetings, etc. relevant to promotion of the JLA's objectives. He mentioned that a very useful such service is provided by SABRE (www.sabre.org.uk) for people interested in the science of research involving animals. The home page of SABRE's website already has a prominent link to the JLA. MW suggested that the DUETs paper could be a good first email alert.

Testing Treatments Card - SPZ presented a template of the proposed Testing Treatments Card to the group and explained that the idea was that it would be used to help increase public awareness about clinical trials recruitment, and the role that patients have in increasing knowledge about the effects of treatments. There was a mixed response to the card from members. SPZ reported that the AMRC is keen to take this forward, but that she unsure how do so. Members were asked to send comments to SPZ.

Action: All

4 Conclude the priority setting cycle of the JLA Asthma Working Partnership. This objective is covered in item 3 of these minutes.

5 Establish two further JLA Working Partnerships. This item is also covered in item 3 of these minutes.

6 Adopt the lessons learned from the piloted working partnerships and other models. This objective was not covered due to lack of time, but members of the SDG are invited to feed back to LF any comments they may have on the 'Task and Activity List' and the 'Questions to be asked' Papers, which have been circulated.

Action: All

7. Reviewed the resources needed to achieve successful partnerships

7.1 JLA bibliography of patient/clinician/researcher matches/mismatches in research priorities/outcome measures.

IC distributed a summary of the draft report for the 'Extending the James Lind Alliance Bibliography', which had been produced by Sandy Oliver and Jenny Gray. IC highlighted the important finding only 9 papers had been identified compared patients' and clinicians' questions with those being addressed in research. However there were many other papers identified of potential interest to the work of the JLA/UKCRC and UKCRN. Members were asked to feed back comments to SO. SC asked the SDG to consider what the next steps for this piece of work could be. PY to talk to SO re incorporating this work into the UKCRC's interest in this sphere. JS noted that it is relevant to the work of the PhD student involved in the JLA work on incontinence. IC will ask SO to arrange for the complete final document to be sent to all members of the SDG for comment.

Action: All

8. Secured funding to support the continued development of the JLA from 2007 to 2010

IC and PS reported that the MRC and the DH have agreed, in principle, to fund the James Lind Initiative (which includes the JLA and DUETs secretariats) until 31 March 2010, but confirmation from the MRC Board is needed.

The MRC/DH Project Group has requested that a clear JLA plan/objective of work programme be drawn up by the end of Dec 2006 for JLA work from 1 April 2007 onwards, so that progress in meeting the JLA's objectives can be assessed towards early in 2008. SC welcomed this development and LF suggested that members of the MIG or SDG meet with the MRC/DH representatives responsible for overseeing the JLI project to discuss requirements for the assessment process.

Action: MIG

PY asked if there is funding (a budget line), to capture the learning and evaluation of the JLA process. It was noted that there was plenty of Asthma WP documentation, which documents the whole process from its conception. However there needs to be some thought about how this is collated, analysed and presented

6. Summing up

SC thanked everyone for coming, and sharing their views and expertise and thanked Marion and Philippa again, for joining the group.

7. Future meetings

PA will put out feelers for meeting dates in September 2007

- **5 February 2007 1pm – 4pm**
- **19 June 2007 1pm – 4 pm**