

Minutes of the 5th Meeting of the Steering Group of the James Lind Alliance, Royal Society of Medicine, 02 May 2006

Participants:

Ms Patricia Atkinson	Administrator, James Lind Alliance Secretariat
Dr Klara Brunnhuber	Commissioning Editor, BMJ
Sir Iain Chalmers	Editor, James Lind Library
Mrs Sally Crowe	Director, Crowe Associates
Prof Glyn Elwyn	Chair, Primary Care, Cardiff University
Mark Fenton	Editor, DUETs
Mr Lester Firkins	Business consultant, Medical Research Council
Dr Anthony Harrison	Senior Fellow, Kings Fund
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Dr Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Mr Nick Partridge	Chair, INVOLVE and Vice Chair, UKCRC
Dr Sophie Petit-Zeman	Director of Public Dialogue, Association of Medical Research Charities
Dr Chris Watkins	Trials Manager, Medical Research Council

Guests:

Dr Ruairidh Milne	Clinical Director, National Coordinating Centre for Health Technology Assessment
Jenny Versnel	Assistant Research Director, Asthma UK
Dr Mark Welfare	Gastroenterologist/senior Lecturer Northumbria Healthcare NHS Trust
Philippa Yeeles	Research Involvement Officer, INVOLVE

Apologies:

Prof Stephen Holgate	Physician, Southampton General Hospital
Dr Marcia Kelson	Director, Patient involvement Unit for NICE
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
Prof Charles Warlow	Neurologist, Western General Hospital, Edinburgh
Ms Maxine Whitton	Member, Cochrane Skin Group

1. Welcome from the chair

SC welcomed members and invited guests, Dr Ruairidh Milne, Jenny Versnel, Dr Mark Welfare, Philippa Yeeles and Dr Klara Brunnhuber (who was attending on behalf of David Tovey) to the fifth meeting of the James Lind Alliance (JLA) Steering Group (SG).

2. Minutes of 19 January 2006

The minutes of the last meeting were accepted.

Matters arising:

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.’*** MK was unable to action this due to changes in the key people involved in the reorganisation of NICE and the HDA. A new chair is now in place and MK will discuss the JLA with them at the next available opportunity.

Item 5 – ***‘MRC call for proposals on methodology research on the implications of research. SO interested in carrying out this piece of work.’*** SO will find out in July the outcome of her proposal to the MRC for a systematic review of questions about effects of intervention.

Item 6 – ***‘Agreement was reached to populate the DUETs database from the clinician’s perspective and Toby Lasserson, from the Cochrane Airways Group, will***

gather questions from specialist nurses. MF informed the group that Toby had not received any response from the nurses to his request for questions.

3. **Membership of the Steering Group**

SC gave an overview of the paper which outlined the Steering Group Membership requirements for the future, and drew attention to the proposed SG matrix which highlighted gaps in the membership, such as lack of non-medical clinicians or representatives from the Health Technology Assessment (HTA) Programme. SC will contact Lynn Kerridge, Executive Director, NCCHTA to discuss the possibility of HTA representation. There were no objections from the attending SG members of their places on the Matrix other than David Tovey who informed the Secretariat (by email) that, as a recently practising GP, he would be happy to be placed both in the clinician and in the media categories if this would help to address the balance of the skill mix in the Steering Group. SC informed the SG members that she would be writing to them later this month to find out if they wished to continue to serve on the Steering Group or step down.

Action: SC

IC thanked members of the SG for their work and contributions to the JLA project and encouraged them all to remain as members. IC also told the group that he, PA and MF would continue to attend SG meetings as members of the JLA Secretariat, but would no longer be official members of the Steering Group.

4. **Affiliates update**

IC thanked CWat for the application on behalf of the MRC for affiliation to the JLA. IC reported that there had been a steady stream of applications for affiliation to the JLA. An updated list of Affiliates will be sent to the SG.

Action: PA

JH has recently been in contact with a new individual Affiliate of the JLA who is very interested in the work of the JLA but is wondering how he can contribute as an individual to ensure the work of the JLA is spread/more known to his counterparts in Scotland. JH raised this as an issue on how the JLA can connect with individual Affiliates or organisations and suggested that the JLA may need to be more proactive. This raised a discussion on what sort of information should be sent to Affiliates, and how? IC wondered if the bibliography that SO was working on should be sent out with copies of newly identified papers of research about research agenda and outcome mismatches. It was felt this might overlap with the work of INVOLVE, which invites people to put papers on the INVOLVE website for the general public to view (www.invo.org.uk, Philippa Yeeles has suggested that if anyone would like further information in relation to this service they should contact, Helen Hayes or Sarah Buckland at INVOLVE). The suggestion of e-newsletters was also raised.

NP said that it must be made clear to Affiliates how often they should expect to be contacted, and that contact should be kept to a minimum, perhaps by sending a personal letter rather than an email.

The issues raised will be taken forward by the JLA Development Group for further discussion.

Action: JLA Dev Group

5. **Working Partnerships update**

Asthma – LF updated the group on the current progress of the Asthma Working Partnership (WP), using a diagram which depicted the stages from Questions to Priority Setting meeting. This promoted discussion and debate some of which is detailed below and continues in item 8.

SC reported that a key decision had been made in relation to the prioritisation process. It had been decided that initially, clinician and patient groups would look at the questions separately in order to group and narrow them down. The two groups would then come

together for a final prioritisation.

GE felt there was a stage missing between stage 1 and 2 of the diagram, which would translate and assemble raw questions into indicative questions. LF asked how and by whom would this be done. IC explained that raw questions would go into DUETs, then indicative questions derived from them would also be added to DUETS.

The issue that important things/questions might be lost in the prioritisation of groups was raised. It was agreed that there was a danger that important raw questions might be lost. MF said that he felt it was up to the clinicians and patients involved how they came to conclusions about priorities.

Mark W stated that methodology was key, to try to minimise biases. He emphasised the importance of drawing on the skills of social scientists researchers. TH has had experience of a similar process and has offered his help with any guidelines that need to be produced.

IC suggested that there should be a description of each stage in the refinement from raw questions through to identified priorities, and a methodology paper written to describe each phase. SC agreed that it was important to report and to be able to trace back via an audit trail. IC also mentioned his concern that the JLA should not duplicate similar efforts being made by others.

Jenny V updated the Steering Group on the progress made by AUK in gathering questions about treatment uncertainties using postal questionnaires and web surveys to their members and visitors to their website. JV has worked with MF to identify overarching categories of questions, and will be sending them to the Working Partnership to identify overarching themes. It was suggested at some stage (as there will be many questions) that a voting exercise should be undertaken. The BTS was invited to circulate the postal questionnaire among their members but this was not taken up. IC expressed his appreciation to JV for the work done by her and her colleagues at AUK.

Epilepsy – LF reported that he had a very good meeting with the Joint Epilepsy Council on the 26 April and he felt there was definite interest in the possibility of a Working Partnership in Epilepsy. The JEC said they would have no difficulty in assembling the appropriate groups for this venture. A further meeting has been set up for 5 July for the JLA to present and discuss with the JEC full Executive Committee.

Schizophrenia – MF reported that he and IC had met with Prof Keith Lloyd (Mental Health Research Network Cymru, University of Wales, Swansea) and Dr Diana Rose (Institute of Psychiatry, London) to discuss the role of DUETs in schizophrenia. The Welsh Office for Research and Development (WORD) has agreed to support the development of DUETs in schizophrenia and epilepsy. A development officer to work on this is currently being recruited as part of a proposed programme of work for the Mental Health Research Network Cymru, and this will lead to collaborative work with Hafal and MIND Cymru. MF described the difficulty of involving mental health patient organisations. SPZ suggested RETHINK (mental illness charity, formerly 'National Schizophrenia Fellowship').

Rheumatoid arthritis – LF reported that his scheduled talk and meetings with Prof John Kirwan (Academic Rheumatology Unit, Bristol Royal Infirmary) had to be postponed due to unforeseen circumstances. IC is scheduled to talk to Prof Kirwan on the 3 May and will feedback the outcome of this discussion.

Action: IC

Ulcerative colitis - Mark Welfare gave a very impressive presentation on his work with patients with ulcerative colitis and its relevance to the work of the JLA. His presentation will be posted on the JLA website and PA will notify the SG when this has been done. Mark mentioned the use of 'Q sort' as a methodology for sorting and prioritising questions/material and he will send a reference to this method to PA to circulate to

members of the SG. Mark also mentioned that the NACC (National Association for Colitis and Crohn's Disease - www.nacc.org.uk) was interested in the JLA and might affiliate.

Action: Mark W & PA

6. Discussion on 'sticking points' in the current model of developing JLA Working Partnerships

The JLA Development Group will address the following 'Sticking Points' which were identified after discussion of the current Working Partnership (and will contact individual members of the Steering Group for guidance).

- Methods for developing questions to aid transparency and help understand how to overcome difficulties with future WP's:
 - Describe (methods paper)
 - Account for decisions
 - Audit trail back to **all** original (raw) questions
- The need for clinical leadership and a clear point of contact for clinicians involved in WP's
- Explaining treatment uncertainty (it appears we haven't cracked this one yet!), (Philippa Yeeles has said she would be interested in contributing her perceptions and thoughts on the issue of 'what does a treatment uncertainty mean?')
- Working with groups/individuals – we describe in our guidance that we work with groups, but these appear to be more bureaucratic, is it worth working with individuals who have linked input to relevant groups?
- Who makes up the partnership? How to decide between patient groups/clinical groups, where we have several interested, and /or have reservations about some getting involved

7. Database of Uncertainties about the Effects of Treatments (DUETs)

MF informed the group that Dr Colin Gelder, Consultant Respiratory Physician, Wales would be taking over the Editorship of the Asthma DUETs. A patient editor has yet to be identified.

MF explained that it was important that the development of DUETs was not tied exclusively to the development of JLA Working Partnerships. There had been a lot of interest from people (such as Prof Keith Lloyd, as mentioned in the note on schizophrenia. Above). IC informed the group that DUETs was also receiving attention internationally, and that colleagues from the Norwegian Knowledge Centre for the Health Services would be visiting Oxford on 27 June to learn more about the work at a meeting which will include representatives from the NCCHTA.

MF reported that NHS Direct may no longer be a source for DUETs questions as their funding is under threat and are currently undergoing reorganisation, and that they do not provide relevant questions for DUETs.

Philippa Yeeles has suggested that it might be worth involving INVOLVE when the DUETs specialist editors roles are being discussed.

IC noted that current funding for the JLA Secretariat and the DUETs project ends in December 2006. A proposal to extend funding until March 2010 will be discussed at the James Lind Initiative Project Board on 15 May. IC will report to the SG on the outcome of the meeting.

Action: IC

DUETs development projects in Wales – Glyn Elwyn Report

The following is a summary of Glyn's report:

1. A bid made to Wales Office of Research and Development (WORD) to undertake a qualitative study of perceived treatment uncertainties, not addressed by systematic reviews, in the area of asthma.

2. This bid is part of a programme of work in this area supported by Professor Glyn Elwyn, Dr Colin Gelder and Professor Keith Lloyd in Wales to support the analysis of query answering services and also a potential analysis of correspondence between clinicians as a way to compare the different ways of populating the DUETS database.
3. A proposal has been prepared by Professor Glyn Elwyn to provide an online consensus method, based on similar work previously done at an international level on patient decision aids. The proposal has been shared with Iain Chalmers and discussion have taken place about the resources required to support this development.

8. **Priority setting in the James Lind Alliance**

SC invited comments on her paper on 'Priority Setting approaches for JLA WPs'. The paper was well received and raised further issues for discussion as detailed below. SC also asked for the groups views on how a prioritization session could be run and what methodology would be preferable.

SC also reported on the meeting the JLA Development Group had had with Dr Francisca Caron-Flinterman and Dr Jacqueline Broerse from the Athena Institute for Research on Innovation and Communication in Health and Life Sciences, Free University of Amsterdam. The meeting was also attended by Jenny Versnel and Dr Colin Gelder. Dr Caron-Flinterman and Dr Broerse were invited to discuss their experience of involving patients in identifying research priorities in asthma. PA will circulate a copy of the notes of the meeting to SG members.

Action: PA

Points raised:

- The following illustrated how the HTA might approach prioritisation: Members of HTA panel consider research questions arriving by a variety of routes, mostly from clinicians, but also sometimes from patients. The process led to the preparation of a vignette and synopsis of previous research and the proposed new research question. It might take about 15 minutes to clarify each question at the prioritisation meeting. It was important not to underestimate the difficulty and time of discussion for each question. The HTA require well constructed research questions for their funding system.
- Ruairidh Milne said that the output needs to drive the process and encompass different kinds of priorities. He also said that the process was all about objectives and that there was no right answer; so the aim is to try to get to products that you want which are sufficient and politically defensible. The product is difficult to visualise which poses a problem for the JLA as it is not clear yet which funders will support JLA priorities.
- IC stated that if research funders ignore and do not respond to priorities which are considered important by clinicians and patients then the JLA would have failed.
- GE said that question refinement into indicative questions (see above) needs to be defensible for JLA to have credibility, and that clear methodology is needed.
- CW said that the MRC works in response mode, and would be ready to fund priorities raised from the JLA process which had identified the importance of the question. This process would also inform clinicians/researchers. He stressed that this way of working can be managed by different funders. He also said that the JLA could be seen as adding polish to the process of prioritisation.
- SP noted that the UKCRC was also interested in the JLA approach to identifying questions. She also wondered if the JLA could find a funder who would be willing and ready to fund the outcome of the prioritisation process.
- Mark W stated that, whole organisations need to be on board with these ideas as a driver and working with UKCRC for example was crucial.

- Are we over-engineering? (This was suggested at a previous asthma meeting)
- LF stated that the prioritisation should be left to the Working Partnership to decide. The JLA's role could be to specify some minimum guidelines, but the JLA's objective should be to kick start and give initial support to a working partnership that becomes self-sustaining.
- NP asked what can we afford to do? What are the financial and human resource requirements from the JLA and the Working Partnership. LF has responded to these issues with a list of key questions about resources etc. for new Working Partnerships.
- SO raised the issue that the participants in this sort of exercise needed to be well informed, and that the following points were things to think about: good agenda questions, long term, what is research? what is researchable? People need to know what they are talking about. What do you want? What is a credible group?

SC will redraft the paper with these points in mind and include a section on the HTA experience (not intentionally omitted!) with suggestions from SO. This paper will be circulated to the core Asthma WP group for decisions, and to the SG for info.

Action: SC

At the next meeting IC will give an overview of the project board meeting on the 15 May (as mentioned above under the DUETs item) and will let the SG know the outcome of the funding proposal for a further 3 years work, and what themes the funders wish to see taken forward. IC stressed that he would be happy if the JLA's objectives were pursued successfully by other organisations, even if not by the JLA. He also restated his concern about the possible duplication of effort.

Action: IC

9. Priority setting in UKCRC-supported research – Nick Partridge

Due to lack of time this item will be carried forward to the next Steering Group meeting on 12 July.

10. Promoting the objectives of the JLA, via steering group members and affiliates

Due to lack of time this item not discussed.

11. JLA work vis-à-vis industry [paper 4] – Iain Chalmers

Due to lack of time this item will be carried forward to the next Steering Group meeting on 12 July.

12. Summing up and clarification of action points agreed

The JLA has reached a critical stage in its development, with 'sticking points' identified in Working Partnerships and DUETs development. The SG has provided a useful steer (and challenge) on the JLA methodological approaches. The key points ranged from reflecting on the endpoints of a JLA process; the resource/funding issues to undertake highly engineered approaches to question development and priority setting; and how to reach a wide spread of opinion and perspectives in any given disease area.

The SG provided some food for thought for the Development Group, and it is likely that we will pick up with individual members to take actions forward. Due to the reduced time available at meetings it was agreed that SG members would receive update papers on each Working Partnership prior to future meetings.

SC would like to again thank Jenny, Mark, Glyn and Ruairidh, especially for their input on methods. SC thanked everyone for coming.

13. Future meeting date:

12 July 2006 1-4pm, RSM, London