

Minutes of the 8th Meeting of the Strategy and Development Group of the James Lind Alliance, Royal Society of Medicine, 05 February 2007

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
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
Ms Philippa Yeeles	Programme Manager, UK Clinical Research Collaboration
Ms Pamela Young	Senior Programme Manager, National Coordinating Centre for Health Technology Assessment

Invited Guests:

Ms Jude Frankau	PhD Student, Health Services Research Unit, University of Aberdeen (Incontinence Working Partnership)
Alexandra Greene	Senior Research Fellow, Health Services Research Unit, University of Aberdeen (Incontinence Working Partnership)

Apologies:

Dr Anthony Harrison	Senior Fellow, Kings Fund
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Prof Stephen Holgate	Physician, Southampton General Hospital
Dr Marcia Kelson	Director, Patient involvement Unit for NICE
Dr Marianne Miles	Patient/Public Liaison Lead, UK Clinical Research Network
Dr Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Mr Nick Partridge	Chair, INVOLVE
Prof Charles Warlow	Neurologist, Western General Hospital, Edinburgh
Dr Chris Watkins	Board Programme Manager, Medical Research Council
Dr Mark Welfare	Gastroenterologist/Senior Lecturer, Northumbria Healthcare NHS Trust

(Some of the above participants were unable to attend due to problems with trains)

1. Welcome from the chair

SC welcomed members, new member Pamela Young, and invited guests, Jude Frankau and Alexandra Greene to the eighth meeting of the James Lind Alliance (JLA) Strategy and Development Group (SDG).

2. Minutes of 17 October 2006

The minutes of the last meeting were accepted.

Matters arising:

Item 5, JLA Objective 3.1 Testing Treatments card - SPZ said to delete this item for the time being as feedback had been on the whole negative.

3. Working Partnerships update

Asthma – SC gave an update on the progress of the Asthma WP, outlining the priority setting workshop planned for the 26 March at the RSM. There will be 30-45 people. The 'Nominal Group Technique' (*involves private ranking and face-to-face discussion*) will be used. Ruth Stewart, Social Science Research Unit, University of London, has been commissioned to do an external observation, and Jude Frankau will also write up an observation from her perspective. IC said this provided an excellent opportunity for the two observers to submit protocols and reports of their work independently of each other, to assess the extent of concordance of methods and results. DT also offered an observer from the BMJ. SC to find out from the WP if this would be acceptable. SC will contact PYO to discuss additional facilitators for the day. So far 18 participants have been registered.

Action: SC

Incontinence – LF gave an update on the development of the Incontinence WP. Letters have been sent to potentially interested participants/organisations, informing them of the initiative on the subject of Urinary Incontinence, inviting them to take an active part in helping to determine where research funding should be targeted. The first exploratory meeting is scheduled for April/May 2007 (exact date and venue to be agreed). So far 7 positive responses have been received.

Jude Frankau, gave a presentation entitled '*Research study on dynamics in establishing a working partnership: an anthropological perspective*'. The following point was raised in discussion after the presentation; What does JF see as the conclusion of her study? JF said that her conclusion of the process would depend on what the JLA wants. IC suggested that the conclusion of the process should be when funders pick up priorities out of the process. LF agreed that obtaining funding for research priorities identified through JLA WP's is obviously important, but that the JLA's role was primarily to facilitate the identification of priorities. IC agreed and added that it would be up to people involved in the Working Partnership, who know the field, to lobby to get their agreed priorities taken seriously. He agreed that the SDG could give moral and perhaps some practical support in attempts to secure funding for agreed priorities, but that it would be up to the WP to develop momentum of its own. SC added that this sort of activity could form part of the JLA objectives in 2008. It was also agreed that JF will give feedback on progress of the study to the SDG at appropriate times.

Epilepsy – LF reported that there has been no tangible progress, and that it is not the JLA's role to drive it. This will be kept in view while the DUETs epilepsy module is being developed. JS said he may still try to organise a teleconference with the clinicians. SPZ suggested that it might be a good idea to contact MIND (National Association for Mental Health).

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

IC gave a report on progress. He explained that DUETs' original purpose had been to serve developing WPs, but over time it had become clear that the WP's and DUETs were developing at different speeds, hence the decision to decouple the two activities. As interest in DUETs was gathering momentum it had been decided that its further development would use the infrastructure of the National Library for Health (NLH) Specialist Libraries (www.library.nhs.uk). IC suggested that Prof Hwyl Williams, Clinical Lead for the NLH Skin Conditions Library (and Coordinating Editor of the Cochrane Skin Group) be invited to a future meeting of the JLA SDG to give the SDG an account of how the NLH Specialist Libraries function and on progress in developing a DUETs Module for Skin Conditions. (*Since this meeting Prof Williams has accepted the invitation, and will attend the 27 September SDG meeting with his colleague Douglas Grindlay*). SC requested that there be some understanding of the NLH site traffic and who uses this portal as this would aid our understanding of how DUETs integrates with NLH.

Diabetes DUETs – IC said that Roger Gadsby, Clinical Lead for the NLH Diabetes Specialist Library, and his colleagues were now the focal point for the development of a DUETs Module for Diabetes.

5. **JLA Objectives**

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

LF gave an overview of the paper which will be used for discussion to agree a "way of working" between the JLA and the UKCRN/C as follows:

- Sharing of knowledge and awareness between JLA and UKCRN/C
- Discuss way of working and liaison
- Discuss how the best can be made of the opportunities for patient engagement
- Discuss and agree how JLA can liaise with UKCRN/C members

LF & SC to meet with PYe & MM on 6 February to discuss the content of the paper, and will continue to meet..

SC said that the UKCRC Patient and Public Involvement Project Group has agreed that the minutes of their meetings can be made available to the JLA SDG. The JLA

will reciprocate with the SDG minutes. IC is currently a member of this group and wondered if the JLA's interest would be better served if another member of the SDG represented the JLA at these meetings. SC, LF PYe & MM will discuss at their meeting on 6 Feb.

LF said that he was in discussion with Martin Lodemore – PPI Lead for the Diabetes CRN - and was waiting to hear whether he (LF) would be able to observe the next priority setting meeting. LF said that he hoped that this would present an opportunity for the JLA to learn from the approach to priority setting within this and other UK Clinical Research Networks.

SC suggested that, if it is not already being done by the UKCRC/N, it would be worth observing all the networks to map how they all approaching prioritisation. A report based on these observations would add value to our understanding of prioritization, and be a tangible outcome for the JLA. GE observed that a description of how research funders and teams prioritise would be very helpful but that the exercise would need to have clearly defined boundaries. Following the meeting with PYe and MM on the 6th December SC to draft an outline of a piece of mapping work on research priority setting in the UK and send this to those interested for feedback.

Action: SC & LF

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

Joint JLA/Lancet conference: How can clinical trialists serve the needs of clinicians and patients more effectively?, 25 June 2007, RSM. DT updated the SDG on the current plans for this event and confirmed that all the invited speakers except John Bell were able to participate. Margaret McCartney, medical columnist, Financial Times, may be able to mention the event in her column. Richard Horton will write a commentary for The Lancet, which will reach a medical audience. It was suggested that a piece could be written and disseminated by INVOLVE to reach their membership/patient groups. It was hoped that members of INVOLVE would be able to attend. It was decided that all the patient leads from the UKCRN/C networks should be invited. It was suggested that perhaps the event could be video (or audio) recorded and a DVD produced.

LF asked 'what was the expected outcome from the day?' apart from the Lancet and other commentaries envisaged. GE suggested that speakers could be asked to end their talks with a summary of their conclusions and proposed action points along the lines of "What should/could change to ensure that clinical trialists serve the needs of clinicians and patients more effectively?". JS also suggested that there needed to be more 'comfort' breaks in the programme.

Joint JLA/AMRC symposia: Should patients tell researchers what to do? If so how?, 17 September 2007, Wellcome Collection Conference Centre. SC gave an overview of the summary of ideas planned for this event. This Symposium will be aimed at the AMRC charities, JLA Affiliates and others interested in the work of the JLA. SC will contact suggested speakers. Date is confirmed as 17th September.

Action: SC

IC asked SPZ to formally thank Simon Denegri for the AMRC's involvement, and DT to thank the Lancet for their involvement with the JLA.

Action: SPZ & DT

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

IC mentioned that he understood that Prof Ray Fitzpatrick had a database of patient-reported outcomes. SC will explore this.

Action: SC

SC informed the group of an invitation to attend the **'Health Coalition Initiative Workshop, 28 March, London.** SC will attend and report back.
Action: SC

4. Conclude the priority setting cycle of the JLA Asthma Working Partnership
Covered in item 3 of these minutes.

5. Establish two further JLA Working Partnerships
Covered in item 3 of these minutes.

6. Adopt the lessons learned from the piloted working partnerships and other models
This objective will be covered at a later date.

7. Review the resources needed to achieve successful partnerships

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

IC gave an update on the completion and findings of the bibliography, copies were distributed to members of the SDG. The bibliography will be posted on the JLA website and the Affiliates (and all on JLA mailing list) will be notified. SO is currently in the progress of producing disease-specific bibliographies, which will be added to the DUETs website.

SC raised the issue of the conflict of disseminating information like this as widely as possible in a timely way, versus the restrictions and time it takes to get published. IC said the bibliography should be shared and made widely available as soon as possible. DT reminded the group that a well placed publication had more potential to influence the clinical community than any other sort of press activity. SC will feed back this discussion to SO.

Action: SC

7.2 JLA systematic review of material in the JLA bibliography

SC asked the SDG for ideas on acquiring funding to do a systematic review on the articles found in the Bibliography. There was discussion of potential sources of funding to take this forward, which included mention of the Cochrane Collaboration's new Prioritisation Projects Fund. (*'A Fund which has been created by the Cochrane Collaboration Steering Group to seek to build on the experience and enthusiasm of entities in the area of prioritisation of key review topics, and better meeting stakeholder expectations*)

7.3 Review of JLA Web-based Affiliates database

LF said that he, PA & SC met with the JLA Web Consultant and the designers of the CHROME CRM web-based database (originally designed for "customer relationship management") on Jan 8, to discuss ways of improving/managing the Affiliates database to aid better communication and engagement. The JLA Web Consultant and the CHROME team have submitted proposals to achieve the above. It was agreed that LF, SC, SPZ & PA to look into this and decide on the best option.

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

SC and LF reported that the business plan for 2007–2008 submitted to CW (MRC) and PS (DH) was accepted with provision that the following is included:

- Add resource allocation to each stream of work
- Put in deliverables/metrics and outcomes of work
- Prioritise what is most important.

6. Summing up

SC thanked everyone for coming, and sharing their views and expertise and thanked Jude Frankau and Alexandra Greene for their input to the meeting.

7. Future meetings

- **19 June 2007, 1pm – 4pm**
- **27 September 2007, 1pm – 4pm**