Minutes of the 20th Meeting of the James Lind Alliance Strategy and Development Group, Royal Society of Medicine, London, 18 Jan 2011.

Participants:

Miss Lizzie Amis	Programme Manager, Patient and Public Involvement Programme, NICE
Ms Patricia Atkinson	Administrator, James Lind Alliance Secretariat
Sir Iain Chalmers	Editor, James Lind Library
Ms Katherine Cowan	Independent Consultant
Mrs Sally Crowe	Director, Crowe Associates
Mr Lester Firkins	Business Consultant, Medical Research Council
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Prof Stephen Holgate	Physician, Southampton General Hospital
Dr Susan Kerrison	Assistant Director Research and Development University College London Hospitals Trust
Ms Emma Malcolm (previously Halls)	Chief Executive, Prostate Action (previously Prostate Cancer Research Foundation)
Prof Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Sir Nick Partridge	Chair, INVOLVE
Dr Kay Pattison	NIHR National Programme Manager, Research and Development, Department of Health
Dr Sophie Petit-Zeman	Head of External Relations, Association of Medical Research Charities
Dr John Scadding	Emeritus Dean, Royal Society of Medicine
Dr David Tovey	Editor in Chief, The Cochrane Library

Apologies:

Dr Brian Buckley	Primary Care Researcher, Cochrane Fellow and Chairman of Bladder and Bowel Foundation
Dr Mabel Chew	Associate Editor, BMJ
Dr Tom Foulkes	Medical Research Council
Mr Derek Stewart	Director, Patient & Public Involvement, NIHR Clinical Research Network Coordinating Centre (NIHR CRN CC)
Ms Pamela Young	Specialist Programme Manager, NIHR HTA programme

1. Welcome from the chair

LF welcomed everyone to the meeting of the James Lind Alliance (JLA) Strategy and Development Group (SDG).

2 Minutes of the 28 Sept 2010

The minutes of the last meeting were accepted.

Actions arising:

Point 3 - What evaluation is necessary to demonstrate JLA achievements? (Priority Setting Partnerships – Are they worth the effort?) – SO has received some feedback to this question, which will be incorporated into the final paper.

Pre-term birth Priority Setting Partnership (PSP):

SO said that funding had been received to progress the Pre-term research project/PSP, with SC as the main JLA lead. The funding is for 3 years and will include a PhD student who will explore the workings of the PSP while in progress.

Urinary Incontinence PSP:

The full report of the PSP by the PhD student has not been received – LF chasing.

JLA and NIHR Evaluation, Trials and Studies Coordinating Centre (NETS-CC)

SC and LF met with Lyn Kerridge and Ruairidh Milne at NETSCC to further discuss their interest in working with JLA after 2013, which appears to fit with their future plans. If tentative plans develop there would be a phased transition 2012-2013, with migration envisaged in April 2013, adapted to dovetail with NETSCC's programme. Next telecon scheduled for 14 Feb.

Follow-up after PSP conclusion
There was discussion on what studies result after the conclusion of PSPs The JLA endeavours to revisit PSPs to keep track of progress, and the findings will eventually be built into the Guidebook. SH to provide details of 2 new trials which have resulted from the asthma PSP.
Action: SH

3. PSP Updates

Prostate Cancer
The Prostate Cancer PSP has had its final priority setting meeting and produced a top 10/11, which will be reported in a couple of articles currently being drafted. The PSP has engaged with NETSCC, which is interested in two of the questions, and the MRC, which is interested in others. EM said that the JLA should use some of the PSP participants as advocates to promote the JLA.

Schizophrenia
The Schizophrenia PSP had its prioritisation workshop earlier this month. Following earlier work by Swansea University to identify patients', carers' and clinicians' schizophrenia treatment uncertainties, this PSP focused purely on interim and final prioritisation. The workshop participants included service users who were not representing a support/patient group, which added richness to the debate and shone a light on areas which clinicians admitted they would otherwise have ignored. The Steering Group is now developing a dissemination strategy to bring the top 10 priorities to the attention of research funders, and to ensure they have maximum impact on the schizophrenia community.

Mark Fenton's valuable input to all the PSPs so far was noted. EM described him as "a legend", suggesting he had changed the thinking among the Prostate PSP participants. LF noted Mark's significant role in the JLA and the PSPs. IC said it was a privilege to work with Mark, whose contribution is pivotal.

4 JLA "Lite": a feasible alternative?
LF presented ideas to generate discussion on the feasibility of a JLA light touch approach. He reminded everyone of the JLA objectives as follows:

- To support PSPs of patients, carers and clinicians to prioritise treatment uncertainties into a list for research funders to address.
- To support and raise the profile of proper involvement for all people with an interest in medical research.
- To gain evidence on how best to prioritise with patients and clinicians collaborating.

LF talked through the five stages of a PSP:

- Initiation
- Consultation
- Collation
- Prioritisation
- Reporting

He described how priorities are determined:

- Establish our partnerships – patients, carers and clinicians
- Collect treatment uncertainties from patients/carers, and clinicians/researchers AND research literature
- Check that they are valid uncertainties and assemble in UK DUETs
- Carry out interim priority setting through consultation with stakeholders – top 20-30 shortlist
- Convene a final shared priority setting workshop, where a 'top ten' shared list of uncertainties is agreed through discussion and ranking
- Publish the results, to influence research funding

LF questioned whether there were a minimum number of steps a PSP must take in order to be recognised as following the JLA process. He raised the issue of protecting the JLA's

credibility, methodology and reputation. He gave an example of the Intensive Care Unit project, which had had some guidance from the JLA, but whose whole priority setting process was condensed into one day. Can the results of this still be badged as a JLA top 10?

SC discussed the method used by the Eczema PSP to refine its priorities, which was also different to the JLA current practice, as they felt there was duplication of effort and economies could be made. Subject to Steering Group approval, the PSP plans to ask people to prioritise their top 3 uncertainties from the beginning. It was felt by members of the SDG that promotion of discussion in the prioritisation process was very important because when multiple perspectives are shared, people's perspectives are often influenced. Members noted some reservations with such a radical change in initial data collection and final priority setting. JS said that this model could defeat the JLA objective. If the discussion is lost how would that impact on the outcome?

EM was concerned that valuable info would be lost if participants identified a top 3 at the start. JH also suggested this would limit the input; JS said the discussion between patients and clinicians was imperative; LA suggested investigating technology which would speed up the process and save costs, although EM argued that it would actually be less expensive to maintain the face-to-face element; NP said the face-to-face workshop was fundamental, but conceded that evolution is part of the process.

NP said potential PSPs want to know the cost of a prioritisation process and what constitutes the essence of the JLA process. NP believes bringing together parties who don't normally get together otherwise is fundamental, and would not want to see this connection lost

SO mentioned evidence from Canada on people changing their minds. This is not yet published but SO will inform the SDG when it is. SO said it was better to go for deliberation as this engages people, promoting more thoughts and ideas.

It was noted that although the Intensive Care Unit prioritisation process did not use UK DUETs data, some of the stages of the processes may have used NICE guidelines.

IC said he had no sentimental attachment to JLA label badge. If the JLA's principles become more widely adopted we should be glad. He said the Intensive Care example is different but good and was stimulated by LF's talk in Edinburgh. He suggested there may be a need to deal differently with PSPs addressing acute conditions (such as intensive care) and longer term ones (such as diabetes or schizophrenia).

JS suggested there are four underpinning features of a PSP to be badged as reflecting JLA principles:

- the UK DUETs approach to collecting methodologically-assessed uncertainties
- equal numbers of patients and clinicians, who have all declared their interests
- a fair means of establishing shared priorities
- publication of priorities, and research commissioned either as systematic reviews or new primary studies.

SC will produce a case study for further discussion, following the final decisions by the eczema PSP, which will be decided by end of March.
Action: SC

The SDG will be informed of further final PSP workshops, for those interested in attending.
Action: SC/LF/KC

5. Type 1 Diabetes

SC outlined the process of the Type 1 diabetes PSP, which included some of the following:

- **Partners**: Diabetes Research Network, Juvenile Diabetes Research Foundation, Insulin

- **Steering Group**: All partners are represented – but multiple hats worn!

- **Process**: Agree Protocol, Agree boundaries of survey and support for wide distribution; Develop taxonomy for uncertainties; Review returns and decide on analysis; Review the long list and agree criteria to reduce 1,259 – 100, Commence consultative priority setting.

- **Survey and initial analysis**: Survey ran between March 2010 – May 2010; 583 respondents – demographic data helped to ensure respondents represent type 1 diabetes community of interest. Total of 1,047 treatment uncertainties suggested. Analysis undertaken by independent information specialist (and some splitting of submissions) = 1,141; 118 added from UK DUETs = 1,259.

- **What have we learnt so far?** JLA PSP has been a great experience so far and the group has worked well despite differences. Having an independent information scientist (very part time) has advantages and disadvantages. Most successful data gathering exercise so far – open questions and wide distribution, plus wholesale support of PSP. The boundaries between type 1 and type 2 haven't been problematic. For the first time the SG agreed criteria to reduce the long list of uncertainties to a manageable number of 100 or under; this will be fed back at a subsequent SDG meeting when it is clear how this process has worked.

- **What is next?** Finalise data analysis by end of Feb 2011. Agree shortlist within Steering Group March 2011. Consult with community of interest for interim voting in April. Final workshop on the 24th May 2011

(*for a copy of the presentation please contact Patricia*)

6. Working with Cochrane

SC is meeting with the Cochrane Airways Group in May to discuss a review of asthma uncertainties in UK DUETs.

SC is a member of the UK Reviews Infrastructure Advisory Group (Chair: Tom Walley). Of particular interest are the NHS Engagement Projects (2010- 2011). SC will hear about their progress at the UK Cochrane Contributors meeting in March 2011. SC will be running a workshop on Priority Setting with Mike Clarke, UKCC – at the Contributors meeting.

A proposal for a Cochrane Agenda Setting and Priority Setting Methods Group is under development with partners.

IC said that the Cochrane diabetes editorial base is in Germany and suggested that SC contacts John Yudkin who is London-based. SC thanked David Tovey for continuing to be an advocate.

8. MRC Specific Objective - Work directly with MRC to understand how it currently promotes patient engagement in funding decisions - and then work with them to produce a plan for advancement:

Since this objective was proposed the infrastructure of MRC has changed and Tom Foulkes is now the main contact for this project. SO and LF have written up and sent a proposal to Tom. LF anticipated this being a useful piece of work but it has not yet been approved.

9. Infrastructure update

Guidebook: KC reported that the Guidebook is receiving almost 3000 visits per month and that a comprehensive update is underway and will be ready in March.

JLA website: this receives over 4000 visits per month. KC is due to review it and make changes to simplify it and create more synchronicity with the Guidebook.

Affiliates programme: since the re-launch in September, Affiliates have increased by 44%, with a current total of 148 organisations and 135 individuals.

Newsletter: the Newsletter's direct reach, which covers Affiliates and the wider JLA mailing list, is about 450 contacts. It is being used to promote the practical aspects of PSPs, sharing good practice, and to contribute to debate about patient and clinician involvement in research priority setting. KC asked that any SDG member with an idea for a feature to contact her.

10. UK DUETs Update

IC noted his role as Chair of the UK DUETs Steering Group and acknowledged that Mark Fenton is much appreciated in NICE as well as by the JLA. IC said that it was currently a challenge as the NICE management process was going through substantial rationalisation, and that the Specialist Collections were undergoing new bids. Part of the new contracts would be the harvesting of uncertainties that come out of systematic reviews. IC he said that he was glad that Gill Leng, the Chief Operating Officer of NHS Evidence, has been supportive of this ever since the inception of NHS Evidence.
New software has been requested to enable the JLA PSP priorities, or any other formal prioritisations questions, be highlighted in NHS Evidence. LA said that lay membership recruitment for the UK DUETs Steering Group was in progress.

AOB Publication of PSP priorities

There was a lively discussion on when a PSP should publish its top ten priorities. There was some suggestion that withholding the results is necessary in order to secure their publication in a journal. Some felt that journals may be reluctant to publish the article if the data were already in the public domain. Others disagreed, suggesting that the JLA should be able to release the top 10 to the mainstream media and place them on the website immediately, and that this was in the best interests of patients. However, concerns were also expressed about the risk of misinterpretation of the uncertainties, which would not yet have been turned into research questions.

JS said he would write to Kamran Abbasi re publicising the top ten results in the JRSM, taking into account the unresolved issue of publication as outlined above.
Action: JS

LF suggested that the MIG discuss a new policy for publicising the PSP top ten priorities, for further discussion at the next SDG meeting.
Action: MIG

LF thanked everyone for attending and for the contributions made.

Future meetings:
5 May 2011
6 September 2011