

Minutes of the 12th Meeting of the Strategy and Development Group of the James Lind Alliance, Chandos House, 13 May 2008

Participants

Ms Patricia Atkinson	Administrator, James Lind Alliance Secretariat
Miss Lizzie Amis	Project Manager, Patient and Public Involvement Programme, NICE
Dr Brian Buckley	Primary Care Researcher, Cochrane Fellow and Chairman of Incontact (Action on Incontinence)
Mrs Sally Crowe	Director, Crowe Associates
Mr Mark Fenton	Editor, DUETs
Mr Lester Firkins	Business consultant, Medical Research Council
Prof Stephen Holgate	Physician, Southampton General Hospital
Dr Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Mr Nick Partridge	Chair, INVOLVE
Dr John Scadding	Dean, Royal Society of Medicine
Mrs Jenny Versnel	Executive Director of Research and Policy, Asthma UK
Dr Chris Watkins	Board Programme Manager, Medical Research Council
Ms Philippa Yeeles	Programme Manager, UK Clinical Research Collaboration
Ms Pamela Young	Senior Programme Manager, National Coordinating Centre for Health Technology Assessment

Apologies:

Sir Iain Chalmers	Editor, James Lind Library
Prof Glyn Elwyn	Chair, Primary Care, Cardiff University
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Dr Susan Kerrison	Assistant Director Research and Development University College London Hospitals Trust
Dr Sophie Petit-Zeman	Director of Public Dialogue, Association of Medical Research Charities
Dr Peter Sneddon	Head of Research Programmes, Department of Health
Dr David Tovey	Editor, Clinical Evidence, BMJ
Roger Wilson	Associate Director PPI, UKCRN; Consumer Member, NCRI Sarcoma CSG; Chair, Prevention Research Advisory Board, NPRI.

Invited Guests:

Ms Ruth Stewart	Assistant Director, Social Science Research Unit, Institute of Education, University of London
Dr Alexandra Wyke	Managing Director, PatientView

1. Welcome from the chair

LF welcomed new members, and invited guests to the 12th meeting of the James Lind Alliance (JLA) Strategy and Development Group (SDG).

2. Minutes of 27 September 2007

The minutes of the last meeting were approved.

3. Urinary Incontinence – Harvesting and Priority setting

BB and SC gave a review of the presentation given at the UI meeting on the 18th March – The aim of the meeting was to establish the progress of the UI WP in harvesting treatment uncertainties for prioritisation, and covered the following objectives:

- *To understand where participants are in the Harvesting Process*
 - *To share issues / problems / opportunities / concerns*
 - *To debate and agree the best way forward*
 - *To agree a firm way forward with accountabilities and time lines*
 - *To start thinking about the Priority setting stages*
- (A copy of the presentations and UI report of the meeting will be sent with these minutes)**

The presentations were well received and the following were some of the comments

raised:

- SH suggested that the information accumulated would be incredibly valuable and should be used to inform educational programmes.
- SO suggested that the UI WP participants might find the HTA resources 'help sheets to work through PICO' useful.
- Is there a mechanism in place to feedback to participants who sent in completed questionnaires, requesting a response?
- BB said that there needed to be more clarity from the JLA point of view of what they do for WP's.
- NP said that the partners within the WP needed to take ownership as far as their own internal processes allow.
- SH said that the outcomes from the process, whether uncertainties or other data would highlight the awareness of UI to more professionals. He also suggested that more explicit effort be made to get industry involved, to inform them of the outcomes of the partnership, and to get more buy in from the wider community.
- AW asked what happens to questions not put on DUETS, and said that the outcomes from the raw database could be used for further work in different fields. BB replied that this dataset (not uncertainties) is a resource for Incontact but also a challenge in terms of the resources to handle the information responsibly.
- SO suggested that perhaps NICE could use the outcomes as a resource. The organisations involved should be made aware that NICE sometimes call for evidence. SO also said that organisations should think about what they have learnt, which could be used for other purposes. LF said that perhaps there could be a link from the JLA website to point interested parties to NICE.

SC is currently in the process of writing some outline plans for the priority setting process, and will take these comments into consideration. LF will organise a teleconference to discuss and agree this plans with the UI WP.

Action: LF to continue management of this WP

4. **Business Planning 2008 – 2009**

LF gave an overview of the business plan and budget, which was agreed. LF said this year the aim was to build up evidence of what has been learnt, to work with models that already have established DUETS, possibly renaming them 'Priority Partnerships' to better reflect the precise role that the JLA undertakes; to build on the profile of the JLA, and that the JLA has been mentioned in several despatches; also to develop and enhance the SDG with representatives of past and ongoing WP's. Katherine Cowan a new consultant will be working along side the MIG team. The performance tracker will be updated regularly and distributed to the SDG at each meeting

Action: LF

5. **DUETs - Progress towards DUETs modules**

MF gave a very brief overview of DUETs saying that the National Library for Health. Specialist Libraries (SL's) were now contracted to do DUETS, so expects to see an increase in DUETs activity over the this year. THE SL's were advised to look for low hanging fruit in the first instance. Funding would be needed to get questions from patients and clinicians. ***(The updated DUETs by Health topic graph will be redistributed with these minutes).***

6. **Working Partnerships update**

Asthma

- Paper submitted for BMJ on 6th May 2008
- Asthma UK are incorporating the priorities into their research strategy, JV confirmed this at meeting.
- JLA still pursuing Respiratory Specialist Library to host asthma findings

Urinary Incontinence

- Meeting held 18th March 2008 for all UI interested parties
 - Full report on JLA website
- Harvesting Uncertainties in progress
 - Final cut-off date 30th June 2008
- Brian Buckley leading on the data entry work stream
His time funded by a Cochrane grant.
- Planning underway for the Priority setting process
 - To be held / concluded by 31 October

Diabetes

- Diabetes SL hosting a meeting on 13th May to explore input to Diabetes DUETs module.
- Long list of people interested in WP, and good links with Diabetes NCRN established

Epilepsy

- Funded DUETs resource available in Swansea under management of Mark Rees, Keith Lloyd and Matteo Cella
- Lester / Mark liaising with Swansea to schedule a meeting where the development towards a JLA WP can commence.
- Patient View went live on survey of their Epilepsy database of patient groups re epilepsy uncertainties, 6th May 2008. JLA funding this.

Schizophrenia

- 158 Uncertainties already entered on DUETs
- DUETs approached JLA for support in priority setting process
- Meeting to be arranged.

Skin

- Research for Patient Benefit Programme confirmed that bid has been successful, with some modifications to detail. This means that in 2009 – 2010 there will be DUETs and WP in Vitiligo and Eczema. JLA has a funding line in the bid, so work should be cost neutral.
- Once finally confirmed, work on a systematic review will start in September JLA aim to get involved early 2009, although will be involved in planning before that.

Chronic Obstructive Pulmonary Disease (COPD)

- Dr Colin Gelder has had no response from the British Thoracic Society and British Lung Foundation.

Interstitial Lung Disease

- *Such as idiopathic pulmonary fibrosis and sarcoidosis.*
- Dr Nik Hirani
Senior Lecturer and Honorary Consultant in Respiratory Medicine
MRC/University of Edinburgh Centre for Inflammation Research Queens
Medical Research Institute
47 Little France Crescent
Edinburgh
- Mark Fenton spoke to Nik Hirani on developing modules for DUET

7. Epilepsy – Patient View Survey

AW gave an update on the Epilepsy survey. She said that the PatientView Database was international, but only UK members have been approached. The aim of the Epilepsy survey is to engage as many Epilepsy groups as possible to find out what their uncertainties are, and possibly interest them in further priority setting activity. Mark Rees, Phil Smith and Mark Fenton have been instrumental in putting the survey together, The collection of data for the survey is due to finish end of July, and has been done entirely electronically and is fully automated. This gives the JLA another model of communication with stakeholders about uncertainties/priorities to consider. Electronic methods have

always been attractive, as they are far cheaper and less time intensive than other approaches adopted so far by the JLA.

8. Priority Setting Mapping Project

There was much debate on the substance of the report produced by TwoCan, and it was suggested that not all of the original objectives had been fully met. SC has asked the SDG to send comments via email. SC will discuss in further detail with those that have substantive comments, and feedback to TwoCan the issues and suggestions that have been raised, it is likely that it will be a better report if the interview data is considered alongside the literature and web review data. LF said that IC raised a concern that what the UKCRN is doing regarding priority setting is also absent from this report. LF will write to the UKCRN and raise this issue. It was noted that with new members of staff at the UKCRN it might be a good opportunity to revisit and explore relations to increase understanding of the UKCRN approaches to priority setting and PPI in this activity.

9. Update on Bibliography

RS tabled a report which gave some preliminary results from the JLA systematic map of clinicians and patients' research priorities. At the end of the report there were two questions that required feedback from the SDG and possible solutions as follows:

1. Who should we include as 'clinicians'?

2. What should we do about the UKCRC research activity codes?

Proposed solution: We propose applying the UKSRC research activity codes to a sub-set of the studies in this map to provide case studies of the research activities identified and prioritised by research participants. The proposed solutions were agreed

Full details can be found in the report (*A copy of which will be distributed with these minutes*).

10. Outcomes in Clinical Research – whose responsibility? – Seminar

The Seminar will be held on the 20th November 2008. Speakers and venues have been confirmed. Once the flyer has been finalised it will be distributed to the SDG.

Action: SC & PA

11. AOB

SC said that GE had offered some strategic leadership, for the JLA to have a more planned approach to writing articles for publication, with stakeholders and partners about the methods and results of JLA activity. SC will discuss further with GE and feedback comments received from the SDG. BB stated that the opportunity of publications of novel approaches to priority setting was perhaps the best 'carrot' for getting clinicians and researchers more engaged with JLA work.

Action: SC

SH said that the JLA should contact Natural England (The Chief execs) and organisations like DEFRA as they are interested in environmental intervention, and would be interested in being involved, and they represent the public. It was also noted that the NICE website offered some guidance. This needs to be thought through at the next MIG and a strategy agreed.

Summing up

LF thanked everyone for coming.

Future meetings

- **30 September 2008, 1pm - 4pm**
- **PA will contact SDG members to arrange meeting date for January 2009**