

# Minutes of the 16th Meeting of the Strategy and Development Group of the James Lind Alliance, Royal Society of Medicine, London, 3 September 2009

## Participants:

Miss Lizzie Amis	Project 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
Dr Susan Kerrison	Assistant Director Research and Development University College London Hospitals Trust
Prof Sandy Oliver	Editor, Cochrane Consumers & Communication Review Group
Ms 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 Morven Roberts	Acting Board Programme Manager HSPHRB, Clinical Trials Manager, Medical Research Council
Dr David Tovey	Editor in Chief, The Cochrane Library
Ms Philippa Yeeles	Programme Manager, UK Clinical Research Collaboration
Ms Pamela Young	Specialist Programme Manager, NIHR HTA programme

## Invited Guests:

Dr Kim Thomas	Associate Professor (non-clinical), Deputy Director of Centre of Evidence Based Dermatology, University Of Nottingham
Mrs Maxine Whitton	Patron of the Vitiligo Society and consumer member of the Cochrane Skin Group

## Apologies:

Dr Brian Buckley	Primary Care Researcher, Cochrane Fellow and Chairman of Bladder and Bowel Foundation (formerly Incontact and the Continence Foundation)
Prof Glyn Elwyn	Chair, Primary Care, Cardiff University
Prof Stephen Holgate	Physician, Southampton General Hospital
Sir Nick Partridge	Chair, INVOLVE
Dr John Scadding	Emeritus Dean, Royal Society of Medicine
Mr Derek Stewart	Director, Patient & Public Involvement, NIHR Clinical Research Network Coordinating Centre (NIHR CRN CC)
Mrs Jenny Versnel	Executive Director of Research and Policy, Asthma UK

## 1. Welcome from the chair

LF welcomed everyone to the meeting of the James Lind Alliance (JLA) Strategy and Development Group (SDG), in particular Kim Thomas and Maxine Whitton, who will present the work of SPRUSD (Setting Priorities for Research with people with Skin Disease), and the vitiligo Priority Setting Partnership (PSP). Jenny Versnel will be standing down from the SDG for a period of 12 months while on study leave. PY will not be attending further JLA SDG meetings on behalf of the UKCRC as her post finishes at the end of the year. However, Nick Partridge, in his capacity as Vice Chair of the UKCRC, will continue to provide a direct link to the UKCRC. LF thanked her for her extremely valuable input and overall contribution to the group.

LF told the meeting that Brian Buckley and Ruth Stewart will be presenting the work of the JLA at the Cochrane Colloquium in Singapore later this year.

## 2 Minutes of 5 May 2009 and matters arising

The minutes of the last meeting were accepted.

SPZ approached John Williams, Head of Clinical Activities at the Wellcome Trust, to find out if

the Trust would be interested in active involvement with the JLA. This remains under discussion, and Simon Denegri, AMRC CEO, will pursue it.

Following a letter of introduction sent to Sir Alex Markham last year, LF and SO are due to meet two members of the OSCHR Board on 14 September. This is an important opportunity to initiate a dialogue about the objectives of the JLA.

The joint MRC/NIHR Project Group for the James Lind Initiative (JLI) has judged that the JLI had made substantial progress in promoting awareness of treatment uncertainties and the importance of taking account of patient and clinician views in research prioritisation, and that the Initiative continues to respond and evolve with the changing health research landscape. The MRC and NIHR have agreed to extend JLI funding, at the current level, until end March 2013, for work involving three main themes:

- UK DUETS and patient friendly information on ongoing trials.
- JLA priority-setting work promoting collaboration between patients and clinicians.
- Preparation of a 2nd edition of 'Testing Treatments' embedded within further development of the James Lind Library.

The main stream of funding will be from NIHR and the MRC Project Group

In the light of developments following the Cooksey Report, the Project Group recognised that the work of the JLI is increasingly within the spectrum of activities led by the National Institute of Health Research and the DH, rather than MRC, and this will be reflected in the relative contributions made by each of these funders to the JLI budget.

The challenge facing the NIHR now is to play its part in the provision of a high quality healthcare environment, including reaching the stage at which awareness of treatment uncertainties and embedding of patient views become mainstream. For its part, the MRC remains keen to explore whether the activities of the James Lind Alliance could help to provide insights into clinical questions to inform the MRC's earlier stage clinical funding, and to promote patient engagement in these areas.

LF said that he was delighted and thanked the MRC and DH for this challenge to the JLA, which will shape future work plans. The JLA Monitoring and Implementation Group (MIG) will discuss this in more depth at its next meeting.

### 3. Priority Setting partnerships – Update

**Skin** – The eczema PSP, part of the SPRUSD Project, due to start early in 2010, will now start later in the year.

**Urinary Incontinence** – The UI PSP top ten priorities have now been published in *Neurourology and Urodynamics* and are on the JLA website. PYo said she has had discussions with Brian Buckley and Adrian Grant about the research required. As requested Adrian has completed a template which provides some further supporting information on the Top 10 uncertainties based on the PICO/EPICOT format. Each one of the questions is considered to be within the remit of the HTA programme and 8 will be submitted to the Programme in October to be considered for A listing and consideration by the HTA Advisory Panels in January for priority research.

IC noted that the HTA had been very supportive of the JLA since its inception, and expressed thanks for this latest example of HTA encouragement. His thanks were endorsed by the other members of the SDG.

**Prostate Cancer** – LF said the PSP was at the harvesting stage and there are potentially 90 organisations involved. The PSP participants are very motivated and have done the bulk of the work themselves, with guidance from the JLA. There are, however, early signs of “healthy” competition between some of the partners and this will require careful management.

**Epilepsy** – KC reaffirmed that the research group funded by the Welsh Office for Research and Development (WORD) is developing its own PSP and that it is anticipated that the uncertainties

will be put into UK DUETs in October.

**Schizophrenia** – KC said there has been renewed commitment. UK DUETs has been populated with uncertainties identified by the researchers in Wales, funded by WORD, and they are open to people submitting new ideas not currently covered. They are in the process of updating the research recommendations in the UK DUETs schizophrenia module and are identifying organisations to take part in prioritisation. The plan is to complete the interim priority setting stage in February 2010, and to identify the top ten uncertainties in April 2010.

**Type 1 Diabetes** – SC said the main outcome from the workshop held in June was that agreement had been reached that uncertainties as a concept in type 1 diabetes is important. No clear way forward was identified at the meeting, but there have subsequently been encouraging conversations with interested parties. Most of the uncertainties highlighted at the workshop have been checked and published on UK DUETS. SC is hopeful that this work will be taken forward.

#### **Other potential PSPs**

**Stroke** – JLA has been invited to join the advisory group for DORIS -Database Of Research In Stroke). LF will contribute at the World Stroke Day event in Glasgow, working with focus groups.

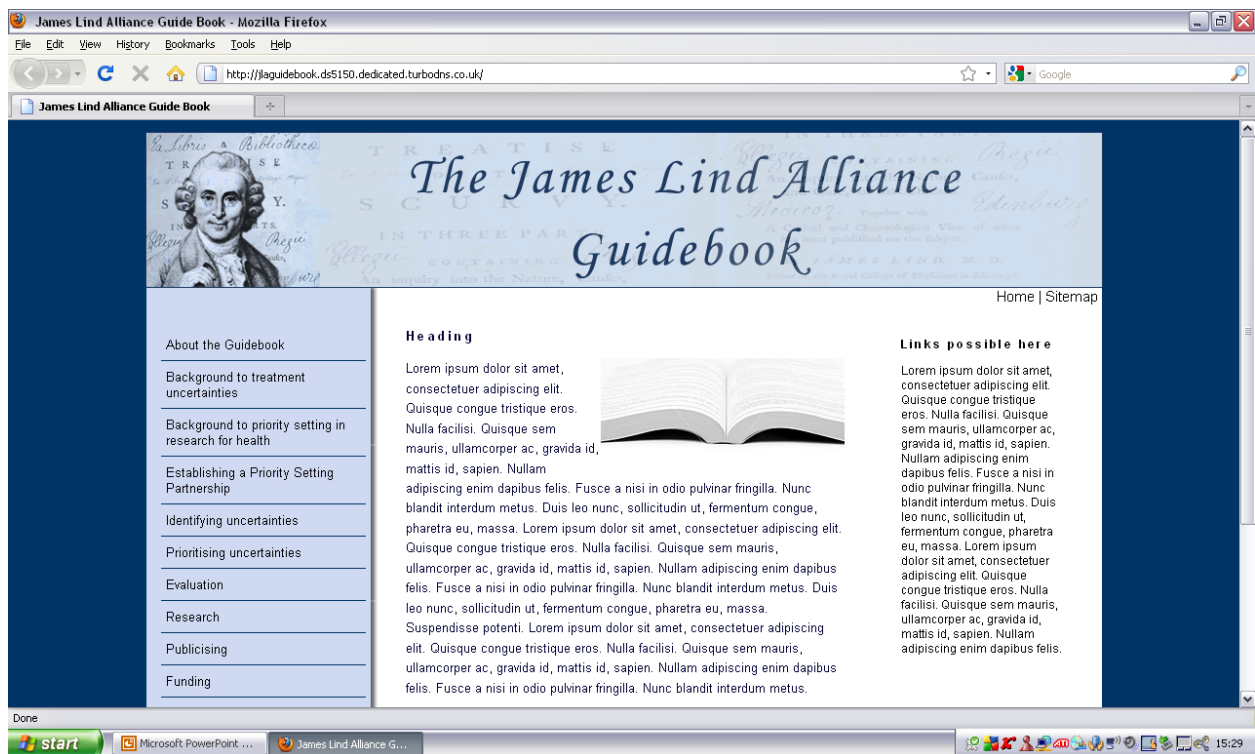
**Intensive Care** – LF met with the Intensive Care Unit team in Edinburgh. They are interested in the treatment of people after transfer from intensive to ward-based care. This will be discussed further in January 2010.

**ENT** – LF met with Martin Burton (NHS Evidence ENT Special Collection and Cochrane Group), who is interested in working with the JLA. LF will make a presentation to the Otorhinolaryngological Research Society later this month.

**Wound Management** (Cochrane Group) – SC has spoken to Nicky Cullum, director of the Wounds Research Group in York, which has secured a NIHR grant and would like to adopt JLA methods. A meeting has been planned later this month. This will be a challenging field for the JLA, because of the need to involve potentially hard to reach patients.

#### **4. JLA Guidebook**

LF said the JLA Guidebook was probably the JLA's single most important activity this year. The JLA was started with a series of disparate guidance documents and an increasing library of publications, coupled with evidence gathered along the way. Although the JLA idea is simple it can be the detail that causes problems to others, especially when they believe it clashes with their own beliefs.



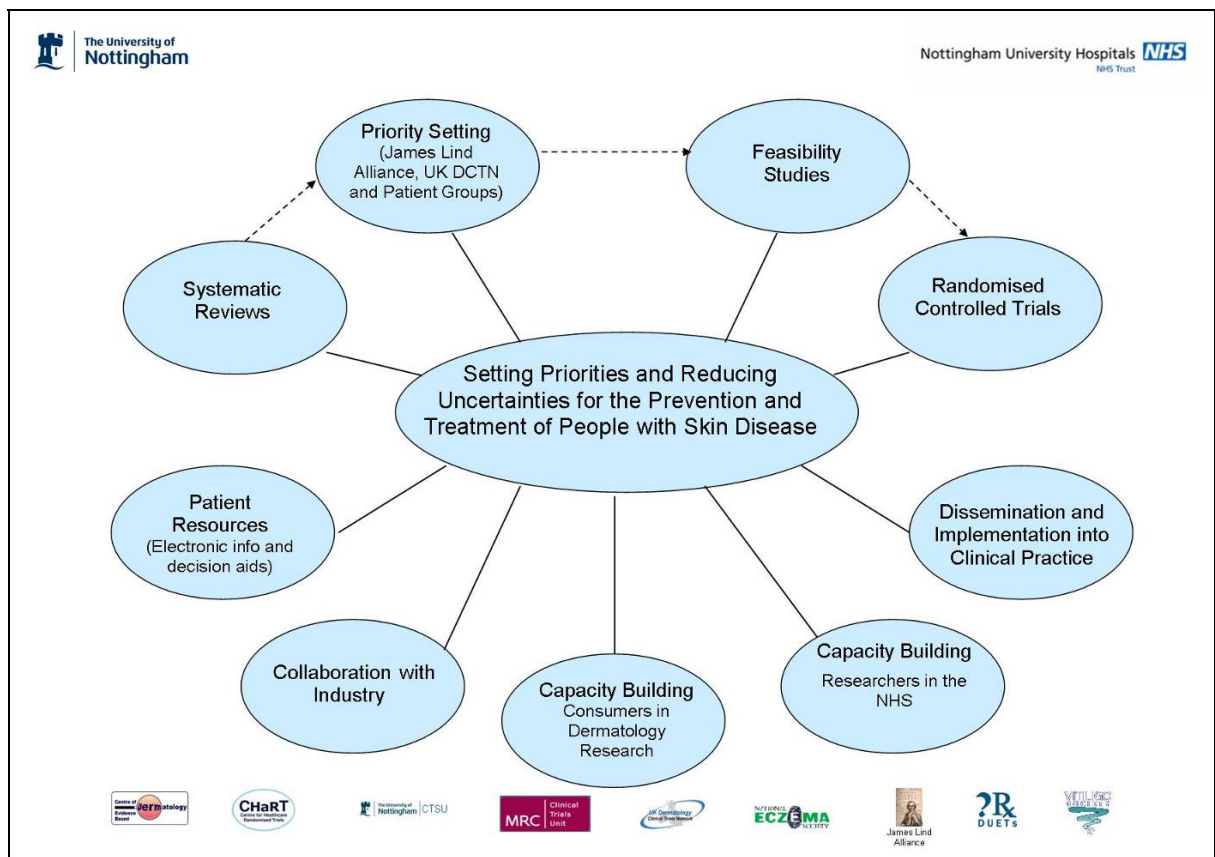
- KC and SO gave a presentation on the progress of the Guidebook, which included the following:
- a recap on the purpose of the Guidebook
  - an update on progress to date
  - an overview of the design concept
  - an overview of Guidebook structure and content
  - next steps for consultation and development

Preparation of the Guidebook is on target, and it has so far received positive feedback from the SDG. IC suggested that research funders should be involved in the Critical Friends Group (CFG). MR said she was happy to give feedback and KP suggested that Jean Cooper Moran, PPI lead at CCF (NIHR Central Commissioning Facility), should feed into the process. KC took note of all the feedback given and will feed into the Guidebook where appropriate. The content of the first draft is currently being reviewed by the MIG, and will then go to the Critical Friends Group for comment. Following further amendments, it will then go online (but not live) for wider feedback, including from those in the SDG who are able to contribute.

A copy of KC's and SO's presentation can be obtained from PA, but will not be available on the JLA website until the Guidebook has been launched.

## 5. **Setting Priorities for Research with people with Skin Disease (SPRUSD) - Vitiligo Priority Setting Partnership**

LF said this project was a large and multi-faceted programme, in which PSPs play an important role. The JLA receives reimbursement for time and input. SC, MW and KT gave a presentation on the partnership between the Centre of Evidence Based Dermatology and the JLA, and the progress of the vitiligo PSP.



A copy of the presentation can be obtained from PA.

**6. Joint event on PPI and commissioning research between UKCRC, AMRC, INVOLVE and JLA**

LF explained that this year the JLA is not hosting any ‘major’ conferences. However, an opportunity arose to join with the UKCRC, AMRC and INVOLVE to assess the evidence of their respective support for patient and public involvement in research funding and commissioning. The aim of the event is to propose a number of actions that have the potential to improve both the process and impact. Funds (from the UKCRC) have been set aside for this jointly hosted half-day workshop/seminar to consider the results of related work by the JLA (Priority Setting Mapping), INVOLVE (Commissioners Survey) and AMRC (Natural Ground Project).

The event will take place in early 2010, and attendance will be by invitation only, with a maximum of 30 participants. Senior staff from organisations that represent key funders and commissioners of public and voluntary sector health research will be invited to participate. It will be co-chaired by Russell Hamilton (NIHR) and Simon Denegri (AMRC) and

**7. Workshop - Does industry listen to patients, and if so, why? – 9 October 2009**

LF said this was a topic that has been mentioned at every SDG meeting, and on which SPZ has been leading. She explained that the JLA, AMRC and National Voices are hosting a ‘think tank’ to explore the extent to which the research agenda of the pharmaceutical industry can be influenced by patients and their representative organisations. This half-day event will be chaired by Simon Denegri, AMRC Chief Executive, and involve invited guests from relevant sectors

**Background & aim:**

AMRC has a track-record of work on relationships between industry and charities, and on patient involvement. The JLA has not so far worked with industry but is interested in the extent to which research projects indicated by their patient/clinician priority-setting partnerships could be appropriately supported by industry.

National Voices, the new umbrella organisation established by and for the voluntary sector, brings together all national voluntary organisations representing users of health and social care, to give them a stronger voice in policy-making. AMRC is an Associate of National Voices, and is delighted that they are partners in this event.

For all three groups, the guiding principle for this meeting is that, notwithstanding the tensions that can exist between the two sectors, there is potential for mutual benefit if charities and/or patient groups and industry work together. The aim of the event is to assess how listening to and working with patients can become a part of the business model for the pharmaceutical industry in developing new treatment and therapies.

**Article – BMJ** – After many iterations, the BMJ article written by SPZ is to be re-submitted as a “Personal View” by her, with input from members of the prostate cancer PSP.

**8. Summary of day**

LF said that, again, this had been a very positive, helpful and encouraging meeting and he thanked everyone for attending.

**Future meetings:**

19 January 2010

11 May 2010