

Minutes of the 21st Meeting of the James Lind Alliance Strategy and Development Group, Royal Society of Medicine, London, 5 May 2011.

Participants:

Ms Lizzie Amis	Patient and Public Involvement Programme, NICE
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
Dr Tom Foulkes	Medical Research Council
Ms Emma Malcolm	Chief Executive, Prostate Action
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	Adviser, Patient Involvement & Engagement, Association of Medical Research Charities
Ms Pamela Young	Specialist Programme Manager, NIHR HTA programme

Invited Guests:

Rosemary Barber	Honorary Senior Research Fellow, University of Sheffield School of Health and Related Research, Section of Public Health
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Apologies:

Ms Patricia Atkinson	
Dr Brian Buckley	Primary Care Researcher, Cochrane Fellow and Chairman of Bladder and Bowel Foundation
Mable Chew	Associate editor, BMJ
Prof Stephen Holgate	Physician, Southampton General Hospital
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)
Dr David Tovey	Editor in Chief, The Cochrane Library

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 18 January 2011

The minutes of the last meeting were accepted.

Matters arising

LF invited members of the SDG to let him or SC know if they would like to observe a Priority Setting Partnership (PSP) final priority setting workshop. The next workshops are as follows:

- Type 1 diabetes: 24th May
- Balance disorders: 31st May

There is also an initial awareness meeting for the Lyme disease PSP on 18th May, which SDG members are invited to observe. Please contact LF.

NP reported that Simon Denegri has been appointed as the new Chair of INVOLVE. LF noted that the JLA has worked closely with SD in his capacity as CEO of the AMRC, and welcomed his appointment. After invitation by LF NP confirmed that he will be pleased to continue to sit on the SDG.

LF noted that the Urinary Incontinence PSP report written by the PhD student will not be published, due to a number of unforeseeable factors. This item will now be removed from the JLA's action points.

3. Dissemination policy

SPZ presented a paper, which she had prepared in response to the lively debate in the previous meeting. The key question is: should we require PSPs to press release their top 10 prioritised treatment uncertainties as soon as they have been decided? Speaking to journal editors, the AMRC, the Science Media Centre and PSPs, SPZ has established that there are various views for and against this. Whether or not a mainstream press route is chosen, it is clear that once the priorities are known, there is no reason why they cannot be made clear, including via the JLA website and on UK DUETs. The JLA must make it clear to PSPs that if the top 10 appear on these sites immediately, it will not prejudice their goals for wider publicity. The JLA can then offer to support the PSP with the media work, including in collaboration with the Science Media Centre. This approach can be developed and included in the Guidebook.

PY noted that the JLA could make it an expectation that the top 10 will appear on the website immediately after the workshop, so PSPs know from the start that it is an important point of principle for the JLA process. **KC agreed to develop a 'top 10s' page on the JLA website as part of her wider development work on the site. PY agreed to sit on a future Critical Friends Group to test the website when it has been redeveloped.**

The technical issue with flagging prioritised uncertainties on UK DUETs was acknowledged and IC noted that this is the most important task for UK DUETs to tackle. **IC asked SPZ to keep the pressure up through him to get the issue resolved.**

TF raised the possibility of asking journals for advance agreement to publish results of PSPs. SPZ suggested drawing up a timetable of final workshops which she will take to the BMJ "uncertainties" page and possibly the Lancet to gauge their interest in covering the results. IC reflected that the BMJ may be preferable, being British, as opposed to international, in its scope and focus, and also because it already publishes a regular column on uncertainties. **SPZ agreed to take a list of the anticipated end-dates for six PSPs to Fiona Godlee at the BMJ.**

SO noted the growing impact of Twitter to publicise initiatives and research. **KC agreed to set up a JLA Twitter profile.** EM also suggested that PSPs should talk to their contacts in pharma to promote their top 10 – **KC and SO agreed to add this to the 'how to get research done' section of the Guidebook.**

4. TF described how the MRC is looking to improve the ways in which patients and non-research clinicians are included in its research priority setting. This has included investigating whether JLA methods can be applied to the MRC. A framework has been set up to develop a pilot focusing on frailty and musculoskeletal aging. LF and SO are working with the MRC on this and a meeting set for 11th May to sign off the way forward

KP raised the question of funding. **It was agreed that KP will check whether or not MRC is reimbursing NIHR for this extra work and in particular LF will advise KP of specific costs so that appropriate cross-charging takes place.**

IC noted that he supports the initiative, but asked if it will cover fatigue. **SC agreed to send details to IC and TF on a fatigue study at Warwick University.**

5 Can the impact of public involvement in research be evaluated?

Rosemary Barber presented the findings of her research, the paper having already been circulated to the SDG

Discussion followed. Points raised included:

- How participants in the research defined the 'feasibility' of evaluation.
- If involvement is fundamentally important, does its impact need to be evaluated?
- The difference between 'can you evaluate the impact?' and 'can you have an impact?'

SC agreed to start developing ideas to see if the JLA can account for where it is having impact.

6 Working with PenCLAHRC

KC described a recent meeting held with the Peninsula Collaboration for Leadership in Applied Health Research and Care (PenCLAHRC), who are also developing methods for involving patients and clinicians in research priority setting. She highlighted areas for learning and collaboration, and next steps. More details of the PenCLAHRC online research question generator are at <http://clahrc-peninsula.nihr.ac.uk/>.

Pen CLAHRC will also be involved in the proposed Cochrane Prioritisation and Agenda Setting Review Group, which JLA are convening with other partners.

7 Planning for 2013

LF talked through the proposal which has been developed with NETSCC to look at possibilities for moving the JLA to NETSCC after current funding expires (March 2013). Abbreviated paper copies were circulated and any SDG members not present will receive these by post. Action- PA please could you send the abbreviated paper out please..

5. Infrastructure update

JLA website

KC reported that the website has been visited 20,000 times since the last SDG meeting in January. The website has been reviewed and is in the process of being updated to make it more user-friendly.

JLA Guidebook

In the same period, the Guidebook had received almost 15,000 visits. It was fully updated in January and the latest version of the downloadable Guidebook is online.

Affiliates

The JLA now has 346 affiliate members (160 organisations and 186 individuals), which is 85% more than the total one year ago in May 2010.

Newsletter

In response to SDG input at the last meeting, the March newsletter contained a feature exploring what happened next to the five completed PSPs and their top 10s. Articles featuring patients and clinicians associated with the PSPs and the conditions they address have been well-received.

AOB

IC paid tribute to SC's recently-published book on patient involvement and suggested that the JLA should provide a copy to each SDG member. **SC agreed to order copies for all SDG members.**

6. Summary of day

LF thanked everyone for attending and for the contributions made.

Future meetings:

In recognition of the fact that the JLA is now moving forward on a strategy that is likely to see migration to NETSCC, and a working party to manage that has been established, it was agreed that future full SDG meetings will in future only take place twice-yearly, in May and November. The September meeting is therefore cancelled, and a date will be found for November and circulated to all members.