

Minutes of the 14th Meeting of the Strategy and Development Group of the James Lind Alliance, Royal Society of Medicine, 23 January 2009

Participants:

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| 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 |
| Prof Sandy Oliver | Editor, Cochrane Consumers & Communication Review Group |
| Sir Nick Partridge | Chair, INVOLVE |
| 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 John Scadding | Emeritus Dean, Royal Society of Medicine |
| Mr Roger Steel | Patient & Public Involvement Manager, NIHR Clinical Research Network Coordinating Centre (NIHR CRN CC) |
| Dr David Tovey | Editor in Chief, The Cochrane Library |
| Ms Philippa Yeeles | Programme Manager, UK Clinical Research Collaboration |

Apologies:

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| Miss Lizzie Amis | Project Manager, Patient and Public Involvement Programme, NICE |
| 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 |
| 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 |
| Mrs Jenny Versnel | Executive Director of Research and Policy, Asthma UK |
| Mr Roger Wilson | Associate Director PPI, UKCRN; Consumer Member, NCRI Sarcoma CSG; Chair, Prevention Research Advisory Board, NPRI. |
| Ms Pamela Young | Specialist Programme Manager, NIHR HTA programme |

Invited Guests:

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| Dr Kristina Staley | TwoCan Associates |
| Mr Anthony Williams | NIHR National Programme Deputy Manager, Research and Development, Department of Health |

1. Welcome from the chair

LF welcomed new members, and invited guests to the 14th meeting of the James Lind Alliance (JLA) Strategy and Development Group (SDG). The new members joining the SDG are: Morven Roberts, MRC, who replaces Chris Watkins; Kay Pattison and Tony Williams, NIHR DH, who replace Peter Sneddon; and Roger Steel, NIHR CRN CC who is replacing Roger Wilson for the foreseeable future. LF offered Nick Partridge the congratulations of the Group on his recent knighthood

LF reflected on the Terms of Reference of the SDG as a reminder of the purpose of the group. LF gave an overview of the progress of the JLA to date as follows:

- The 'Outcomes in Clinical Research – whose responsibility?' Conference held in Nov 2008 was well received.

- The Urinary incontinence Priority Setting Partnership (PSP) (formerly known as Working Partnership) final priority setting meeting was held in Nov 2008. A report of the day will be put on the JLA website. A paper of the process will be submitted to the BMJ by Brian Buckley. LF said that the lessons learnt from the UI experience will be used to inform the toolkit/protocol for future work with PSPs.
- IC said UK DUETs is now incorporated in the National Library for Health (NLH), and overseen by the NLH DUETs working group. Most uncertainties will added to UK DUETs through the NLH Specialist Libraries. The NLH is in the process of becoming incorporated as part of NHS Evidence, NICE.

2. Minutes of 23 January 2009 and matters arising

The minutes of the last meeting were accepted, with a minor amendment in item 8, last paragraph, as requested by JS.

3. Scoping Research Priority Setting (and the presence of PPI in Priority Setting) with UK clinical research organisations and funders

SC gave an overview of the project in which the JLA commissioned TwoCan Associates (Kristina Staley and Bec Hanley) in early 2008 to scope research priority setting with a wide range of research funding organisations in the UK. The aim of the scoping exercise was to find out whether and how clinical research organisations set research priorities and whether and how patients and the public are involved in this work. The findings of this exercise will increase the evidence base on priority setting in research.

KS gave a presentation of the process and findings of the work which involved:

- A review of the websites of UK clinical research organisations.
- Telephone interviews with research managers.
- A brief review of the literature on peer review and Patient and Public Involvement (PPI) in making funding decisions.

(A copy of the presentation will be sent with the final draft of these minutes)

This work was undertaken in parallel with other related work on PPI in research by INVOLVE, the UK Clinical Research Collaboration (UKCRC) and the Association of Medical Research Charities (AMRC). The final report was compiled with feedback received from the JLA SDG, INVOLVE, UKCRC and AMRC.

There was some discussion about the differences between commissioned and response mode research funding. KP noted that commissioning research is more expensive than responsive funding, but felt that programmes of research could benefit from JLA input. There was some discussion about the merit of peer review as part of the commissioning process, with varied experiences of wider stakeholder involvement.

LF reminded the group that whilst the JLA could point out the problems with the current system, if research funders didn't think that there was a problem then JLA providing a solution was unlikely to be beneficial!

IC said Stephen Holgate commented that calls for the assessment of breathing exercises in asthma would never have come up if they had not emerged as a result of the JLA process. This had shown that patients come up with different questions from researchers. IC said that questions that people want to see addressed do not always require new research, but require assessment of what evidence is already available, but some funders still do not see systematic reviews as research.

The outline findings of this work were presented in a workshop at the 2008 INVOLVE conference. Feedback from workshop participants highlighted three main themes:

- **Challenging the research culture** – “Need for a balance between curiosity driven research and commissioned research. Include ‘real ways’ for researchers and the research to change patients’ lives as part of the grant and grant outputs.”
- **Sharing best practice in identifying priorities** – “A translational role to co-ordinate and energise priority setting and make links to peer review and commissioning.”

- **Develop and support commissioning** – “Ensure that priorities influence policy.” “If research generated in this way benefits patients/clinicians more, then it will sell itself”

SO said the scoping study that she and Ruth Stewart had conducted concluded that (1) very few people are working with both patients and clinicians to identify research priorities (this is a JLA strength); and (2) relatively few people identifying patients' or clinicians' research priorities report a direct link with funds to support the research prioritised (this is a real need - bridging between patients, clinicians and research funders. This is a JLA opportunity).

In considering how to bring patients and clinicians together (for 1) and research priorities and research funds together (for 2), clarity is needed about the appropriateness of different models for different circumstances. Circumstances differ in terms of the different stages in the research process (setting the scope for research funders, advertising research funders, scrutinising research proposals, making funding decisions, conducting the research, reporting the research, and getting the research into decision-making). Circumstances also differ in terms of whether research programmes are commissioned or responsive. This is very important. SO said this explains why she has seen peer review as a poor mechanism for stakeholder involvement (in the HTA, a commissioning programme) and KS has seen it as effective (in the MS Society, a responsive programme). The reason it is different is that peer reviewers can usefully comment on the research question in responsive programmes but not in commissioned programmes, because that is done earlier in the process in commissioning programmes.

LF asked the group to think about what the JLA should be doing, and how the challenges could be turned into tangible output.

SC asked how the JLA could nurture and supplement these organisations and encourage them to use the outputs from JLA PSPs.

It was decided that as this is quite a lengthy report, it is best used internally, but a brief summary of the findings should be shared more widely.

In conjunction with this project SC did a web review of the UKCRN Topic Specific Research Networks, which had not been included in the scoping project. This was done with a view to comparing the findings from the two approaches. The JLA is interested in how they develop their research ideas. The outcome of the review helps the JLA to understand what the Clinical Study Groups do. Since the review has finished, RS has offered to work with the JLA, and an outline proposal is being considered for next year's business plan, which involves working with Clinical Studies Groups more closely on issues of priority setting. RS said the review demonstrates the scope for the Networks to improve the way they communicate through their websites.

The web review will be published on the JLA website after SC has updated it with all comments/feedback received.

Action: SC & PA

IC said that the TwoCan Scoping project and the web review were both really important pieces of work. Things won't change until captains of research are on board. People such as Stephen Holgate, who sign up to this agenda, are rare. It is quite reasonable for the JLA to challenge leaders of academia to show that their expressed commitments to public and patient involvement are sincere, not tokenistic, and reflected in practice.

SPZ suggested writing to Wellcome to ask them how seriously they are committed to PPI. SPZ will follow this up.

Action: SPZ

LF thanked everyone for their feedback on the TwoCan report.

4. JLA – Year 3 and beyond

LF said there is a need for a vision of where the JLA is heading and to develop something that can continue, even if the JLA itself does not.

IC said that over the next month or two he would be writing to Declan Mulkeen, the chair of the MRC/DH Project Group, with a revised proposal on behalf of the James Lind Initiative and the JLA.

KP said that the DH usually responds to proposals in responsive mode and they would like to be told what works/what is gained, and what they would lose if the initiative was discontinued. KP said the MRC/DH should be considered as a single source of funding.

The following points were raised:

How will the JLA seek to take things forward and extend its work into the future?

- A succinct business plan is needed, which should include the impact of current work, and its benefits. It is important for funders to understand what works, and what the impact of its loss would be.
- If the JLA ends in 2010, what would have been achieved? What would be lost?
- If continued beyond 2010, what will be achieved?

Taking outputs to the next stage

- Includes moving the priorities forward.
- Developing a protocol of how PSPs work and guidelines to get there.

Working more closely with other groups such as Cochrane

- Ensure public investment in JLA/Cochrane is noted.
- Meet with HTA to examine similar aims.

Engaging 'captains' of academia

- Make stronger links with the Wellcome Trust (e.g. their Head of Policy)
- Ascertain who is actively supportive.
- Don't waste energy on those just giving public involvement lip service.
- Make links with the Service Delivery Organisation (www.sdo.nihr.ac.uk) – Pamela Young/Keiren Walsh.

Understand what a patient is

- Look at how researchers stereotype patients.
- Find out what organisations think they're getting when they engage patients.

Clarity on the appropriateness of different PPI models for different purposes

- This is an area which has grown very fast.
- Examples and explanations are needed to guide people.
- The key sources are the JLA, INVOLVE and the UKCRC.
- We should examine how other partnerships have worked, but also focus on developing a substantial number of uncertainties.
- Be clear on the levels of involvement from people in different groups and settings, and those with different skills and experience. BUT – are other groups doing this already, and if not, does the JLA have the resources to do it?

Communication

- Focusing on existing partnerships to lead by example.
- Look at work which emerges, then focus on how this is communicated.
- Everything the JLA does should be linked to practice.
- Very few organisations are prioritising transparently, so the JLA needs to communicate this.
- Make use of DUETs as a useful product to engage people on uncertainties, then to gain willingness to prioritise.
- The key challenge is winning hearts and minds.
 - JLA needs to show the benefits of the JLA process to convince the sceptics.
 - This may mean revisiting the JLA's basic objectives.

KP said the JLA needs to challenge big organisations, knock at doors with a good product, and look for 'low hanging fruit'.

LF will embody these thoughts within the 2009 – 2010 Business Plan.

Action: LF

5. Supporting future Priority Setting Partnerships

KC tabled the draft Priority Setting Protocol and Guidebook/Handbook project plan for 2009, asking for further guidance from the SDG. LF emphasised that the Guidebook and Protocol are a major output for the JLA this year and will ensure that the good practice developed by the JLA is documented and made available to other organisations to consider and use, whether or not the JLA continues beyond next year. The following suggestions were made:

- This will be a useful resource for people who are new to the JLA process.
- Flexibility in using the guidance should be encouraged.
- The guide should be evidence-based.
- The Cochrane Reviewers Handbook is a good example of a useful online tool.
- The JLA Guidebook/Handbook should state that the JLA way of working with patients/clinicians appears to be very rare, if not unique.
- The potential cost of carrying out a PSP should be included.
- Management of the priority setting process is a key feature.
- Administration needs/requirements should be clearly set out.
- The requirements of people's time should be included.
- Show to funders what they would get at the end of the process for the amount of resource invested.

It was agreed that a group of independent participants should be recruited to inform and critique the development of the Protocol and Guidebook/handbook. KC noted that, at a later stage, members of the SDG would be consulted on the launch of the Protocol and Guidebook/handbook , including who to involve in endorsing it.

KC will incorporate the feedback received into the next draft of the project plan.

Action: KC

6. Summary of day

LF said it had been a very enjoyable and productive meeting and thanked everyone for coming.

7. Future meetings:

5 May 2009

3 September 2009