

## **Report of the JLA Community Workshop: 50 Completed Partnerships and Beyond**

**23.11.17**

### **Glossary**

JLA	James Lind Alliance
NIHR	National Institute for Health Research
PSP	Priority Setting Partnership
RCT	Randomised Controlled Trial – fairly compares different interventions.
Systematic Review	Combines evidence from existing studies.

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## 1. Introduction

The purpose of the day was to bring the JLA community together to:

- Consider the continued development of the PSP process
- Consider key issues for the JLA including how we define uncertainty
- Share learning from past and present PSPs
- Consider the future of the JLA.

It was important for the JLA Executive<sup>1</sup> to hear the views of the wider JLA community about these points and we're very grateful to everyone who attended, and for all of the enthusiastic discussions that went on. Attendees included patients and clinicians from past and present PSPs, former and current JLA Advisers and the JLA Secretariat, information specialists, patient and public involvement specialists, patient advocates, international stakeholders, priority setting specialists, NIHR senior managers, and the midwife of the JLA - Sir Iain Chalmers. We have received very positive feedback about the day, including comments about the collaborative atmosphere, and feeling valued and supported to take part. A full list of attendees is included at Appendix 1.

The influence and reach of the JLA has grown, with a ramping up of JLA activity year on year. 59 JLA PSPs have now been completed, with 14 PSPs completed during 2017 to date<sup>2</sup>, compared to 8 PSPs in the five years from 2007 to 2011, for example.

The health and care landscape has changed very considerably since the JLA was set up; including in the way services are provided and in the health needs of an ageing population, increasingly living with multiple health conditions.

There has been an explosion in global research, and in the research portfolio of the NIHR. The JLA was set up originally to feed one large research programme i.e. the Health Technology Assessment programme. The NIHR now has 9 research programmes<sup>3</sup>, and there has also been a significant growth in charitable funding of health research.

Against this backdrop, it seemed timely to engage with the broad community of interest of the JLA, to consider how we can remain true to the founding principles of the JLA whilst responding and adapting to new contexts.

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<sup>1</sup> The JLA Executive comprises the JLA Advisers and JLA Secretariat (based at the NIHR Evaluation, Trials and Studies Coordinating Centre), together with the Guidebook.

<sup>2</sup> Figures correct at December 2017.

<sup>3</sup> The 9 research programmes of the NIHR are: Efficacy and Mechanism Evaluation (EME), Health Services and Delivery Research (HS&DR), Health Technology Assessment (HTA), Invention for Innovation (i4i), Programme Grants for Applied Research (PGfAR), Public Health Research (PHR), Research for Patient Benefit (RfPB), Systematic Reviews (SR), Policy Research Programme (PRP).

## 2. Defining and verifying uncertainty

The definition of treatment uncertainty has been fundamental to everything the JLA does. The current JLA definition of treatment uncertainties is:

- no up-to-date, reliable systematic reviews of research evidence addressing the uncertainty about the effects of treatment exist
- up-to-date systematic reviews of research evidence show that uncertainty exists.

### 2.1 Is the current JLA definition of treatment uncertainty still appropriate?

As the JLA has matured, it seemed fitting to take a step back and assess whether this definition is still appropriate, or whether changes need to be made. As well as 'treatment', many PSPs now also look at cause, prevention, diagnosis, prognosis, care, awareness and lifestyle options. Scoping is currently led by PSPs themselves, with guidance from a JLA Adviser. PSPs are self-determined and self-funded, treatment is not always the main issue, and listening to patient and clinician concerns is central to the JLA process. PSPs need to generate outputs that they feel are relevant to them, and that they can work with.

This potential widening of scope does have implications, including for: the complexity of communication; the volume of data; the resources needed; the type of verification process needed (considering sources of evidence in addition to, or instead of, systematic reviews); the type of research that may be needed to address the priorities; engagement with different funders; potential risks to the robustness of the method.

In light of the changing landscape of health and social care, JLA PSPs are, in practice, already applying flexibility to the current definition. For example, the Palliative and end of life care PSP (2015) had to have a very different focus to many PSPs given that palliative care is not curative, aiming rather to improve quality of life. Clinical research in this area concerns relief from symptoms, and 'care' combines psychological, social and spiritual support; it is broad by its very nature. Many of the research priorities generated during the priority setting process were broad, and needed further work in order to define more specific research questions. The out-of-scope data, and the stories that survey respondents told, has the potential to provide useful insights in areas where there is very little existing evidence to inform possible interventions, or where qualitative research might be needed as a first step.

The Physiotherapy PSP is currently underway. It is not focused on a single condition or patient group and is generating broad priorities, which could produce multiple research questions. This reflects the changing nature of the patient population, which is ageing, has seen a rise of long-term conditions and non-communicable diseases, and an increase in multimorbidity.

The Schizophrenia PSP (2011) used the traditional definition of treatment uncertainty, and six of its Top 10 were commissioned by the NIHR Health Technology Assessment programme. In contrast, the later Depression PSP (2016), led by the charity MQ in order to

commission mental health research, observed a more empowered patient voice within mental health services by that time. The pressure of those voices led the Steering Group to embrace a scope that included the cause, diagnosis, treatment, care and prevention of any form of depression, and to move away from defining uncertainties using systematic reviews alone. One of the Depression PSP's Top 10 included the impact of depression on employment.

In considering making any changes to the current definition of treatment uncertainty, care is needed to ensure that the JLA method continues to be robust, consistent, transparent and fair.

## 2.2 How should we define uncertainty?

At present, the traditional JLA definition of treatment uncertainty is applied flexibly to fit a particular PSP's needs, with the guidance of JLA Advisers. Perhaps this is sufficient: 'if it ain't broke don't fix it'? However, there was strong feedback that the JLA Guidebook definition should reflect what actually happens in practice, and that the current definition is too restrictive and should be modified.

Iain Chalmers confirmed that the original definition was not intended to be restrictive: JLA priorities are about what is done to help people with health problems, and to try to prevent them.

It is important for the JLA Advisers to clearly articulate the implications of broadening scope, particularly in terms of workload and resource, and the need for the Steering Group to discuss what might happen to questions that are excluded as being out-of-scope. Regardless of the defined scope, people will respond with questions that are important to them, and this is valuable data. The JLA partnership approach can help span the disease model and the care model.

The following new terms to define uncertainty were suggested: "evidence uncertainty"; "unanswered research questions"; "questions that patients / clinicians want answered through research"; "questions that the partnership want answered through research"; "management uncertainty"; "intervention uncertainty". The pros and cons of "uncertainty" versus "unanswered" were discussed.

## 2.3 How should we verify uncertainty?

It may be helpful to distinguish between the **principle** i.e. a 'researchable gap' has to be established before funding new research, and the **methodology** i.e. robust determination of the evidence gap.

Pragmatic decisions also have to be made; balancing the energy and momentum of the PSP with the level of detail of the evidence checking. There was some interest in exploring whether the process would be more efficient if the very detailed evidence checking was applied to the Top 10, rather than to a much larger number of questions earlier in the process. For some PSPs, very few if any of their research questions were excluded when checked against systematic reviews. Even a very thorough systematic review may not

answer a broad research question in full, and some would argue that a large, high quality trial can generate more reliable findings than a systematic review of several small trials.

There was a feeling that the JLA Guidebook should provide detailed guidance about the range of evidence checking strategies that it may be appropriate to use, including ways of researching systematic reviews in addition to Cochrane (for example the Joanna Briggs Institute). The discussion included questions about hierarchies of evidence, the checking of ongoing trials, and the rigour of qualitative evidence. Qualitative research can be particularly helpful for quality of life questions. PSPs need to ensure that they have a plan and relevant expertise in place to verify the type of questions that emerge.

There should be no compromise on the robustness of the verification process. Systematic reviews do not have to include Randomised Controlled Trials exclusively, they can include reviewed social research too. Cochrane Intervention reviews now include qualitative and implementation research embedded within, or associated with, the trials. It was noted that the NIHR Innovation Observatory in Newcastle may be a potential resource of systematic reviewers for JLA PSPs.

A PSP's Top 10 is not expected to be a list of immediately usable research questions. A further stage of work is likely to be needed to develop the research priorities into fundable research questions. One overall research priority may result in a number of specific research questions. Consideration should be given as to whether this work needs to become a more formal part of the JLA process: a 'PSP 2'? This could include building in greater planning for 'future impact' when a PSP first starts to define its scope, and a continuation of the collaboration between patients and clinicians after publication of the Top 10 to maximise implementation and impact, and to help honour the original meaning of the priorities. It may be appropriate for a JLA Adviser to be involved at this stage too.

It was noted that the NIHR does look beyond the Top 10 too, so a PSP's wider priorities are not lost if they don't quite make it into the Top 10.

A potential risk of building in strategies to link with research funders early in the process, may be for PSPs to be led by what will be funded: PSPs also have a role in changing the research funding agenda. Wider impact includes patient empowerment, peer support, clinicians changing their practice, increased public awareness and encouragement of relationships with other stakeholders in the area.

The discovery of 'unknown knowns' can be an important result of the PSP process, and these need to be publicised widely.

### 3. The future of the JLA

The JLA community is growing and embracing different contexts, languages and cultures. Canada has been a particular champion of the JLA, and PSPs have also been completed or are underway in the Netherlands, Germany, and cross-country including New Zealand. There is interest in starting a PSP in maternal health in Uganda.

It is important that the JLA is not constrained, rather that its value is noted, the ethos and principles behind it recognised, and consideration given to the potential implications of its evolution.

Valuable insights about the experience of being part of a JLA PSP were shared by patients and clinicians. Equal collaboration between patients and clinicians is powerful, and is distinct from 'PPI' (public and patient involvement). It was suggested that this collaboration is a model for multi-disciplinary working in practice.

Practical issues in Canada have included the increased expense and logistical difficulties of working across six different time zones within the same country. A limitation across countries, including in the UK, has been contacting frail, marginalised and /or disadvantaged populations via the traditional survey methods. In Canada, including the indigenous population has also been challenging. The Multiple Conditions in Later Life PSP, based in Newcastle, is reaching frail, elderly people through in-depth face-to face interviews. This is very resource-intensive but is proving to be effective.

Most often, PSPs in other contexts follow the full JLA process, with a JLA Adviser. Occasionally, PSPs have been carried out 'in association with' the JLA; for example, some PSPs in Canada followed the Guidebook in full, but did not use a JLA Adviser, and so their Top 10s are not published in the same way on the JLA website.

The University of Nottingham has been involved with many PSPs. They have all been the same, in that they have been JLA PSPs, but they have all been uniquely different. The value of a JLA PSP includes: ensuring that the most important questions are researched and that finite research funding is spent wisely; increasing the chances of changing practice and having an impact because you have identified the right questions; increasing success with research funders, particularly for less known areas. Nottingham has also identified benefits to the community of users, with research being developed and funded into the topics that were prioritised, networks being developed with interested and engaged stakeholders, and maps of systematic reviews being created as part of the evidence-checking process. The Eczema PSP has had particular research funding success; 93% of its priority topics are being, have been or will be, actively researched.

The [making a difference](#) section on the JLA website records any research the JLA is aware of that is addressing, or has addressed, research priorities highlighted by JLA PSPs. Encouraging more research in a particular health area is usually the main objective of JLA PSPs. People who have been involved in PSPs say their work has made a difference in other ways too. It has increased awareness of the health issues they are interested in and encouraged relationships with other stakeholders in the area. Patients have felt empowered

by the contributions they have made to PSPs. The collaborative process has changed the way in which patients and health professionals view and understand each other, and in some cases has changed how clinicians practice medicine.

### **3.1 What does it mean to be a JLA PSP?**

There was wide agreement that the JLA process should be flexible and adaptable, whilst staying true to its core values of:

- the principle of inclusivity, with patients, carers and clinicians working together as equal partners
- methodological transparency
- the declaration of interests, with the exclusion of non-clinician researchers (for voting purposes), and the exclusion of groups/organisations that have significant competing interests, for example pharmaceutical companies
- a commitment to using and contributing to the evidence base
- being guided by an independent JLA Adviser.

### **3.2 Protection of the ‘brand’, accreditation and governance**

The JLA Adviser – independent, but recruited, trained by and connected to the secretariat - is seen as the key to quality assurance of PSPs. It is an advantage that they are expert facilitators rather than having expert knowledge of PSPs’ specific health areas; they are not driven by vested interest.

JLA Advisers are key to:

- maintaining the democratic process
- adhering to the process and ensuring rigour
- assuring quality
- the governance and structure of the JLA.

There was discussion around whether the ‘JLA brand’ can be ‘abused’ and whether it needs to be protected in some way. It is not ‘owned’ by anyone and there are risks attached to that, but this also enables it to work as a ‘social movement’ and grow, flex and adapt, which is a core strength.

At present, publication on the JLA website provides a stamp of accreditation, but a more in-depth accreditation process could be developed, incorporating high quality reporting. The NIHR values the quality of JLA outputs because of the rigorous process that has been followed. It is important to ensure that other research funders are aware that JLA priority setting is distinct from other priority setting processes, and that they can identify when the JLA method has been followed in full.

It was noted that Cochrane has a network of groups internationally, which the JLA could perhaps link with.

Governance of the JLA currently rests in the combination of the JLA Guidebook, the JLA Advisers and the JLA Secretariat, which together form the JLA Executive, supported by the

NIHR. Different possible models were discussed – such as a charity steering committee model, for example. These will continue to be considered, including in the context of a potential international network and / or franchising model.

A reflective approach was encouraged, including a more formal evaluation of the JLA so far, comparing it with other methods of priority setting. Further suggestions for areas to focus on included: ‘gaps’ in the health areas addressed by PSPs so far; how long a Top 10 remains valid for; how to increase diversity of participation; how to measure impact.

### **3.3 The JLA in 5, 10, 15 years....**

The success of the JLA could mean that in the future it is not needed, as its core principles have become the standard way of setting research priorities. However, it has a long way to go in gaining more widespread recognition.

It is estimated that 85% of all health research is being avoidably wasted. One in two clinical trials do not get published, so the information available is heavily biased.<sup>4</sup> There must be no compromise on the robustness of the JLA method if it is to continue to redress the balance. The JLA makes it more likely that health research will find answers that make a meaningful difference. Its impact should be maximised.

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<sup>4</sup> Chalmers I and Glasziou P (2009 and 2016)

## 4. Next steps

The JLA Executive will continue to reflect on all the issues discussed, and to engage with the wider JLA community about these. So far, the following concrete next steps have emerged:

- ✓ There was a high level of agreement that the current JLA definition of treatment uncertainty should be modified.

 Consider the best form of words for a new definition of 'treatment uncertainty'.

- ✓ There should be no compromise on the robustness of the verification process. The area of evidence-checking is complex, and related to the scope of a PSP and the types of questions that are generated. Further guidance in the JLA Guidebook would be helpful, together with consideration of the most effective timing of the evidence checking process.

 Review and add to the current evidence checking guidance in the JLA Guidebook.

- ✓ Governance of the JLA should be reviewed, including in the context of a potential international network and / or franchising model.

 Consider different possible models of governance for the JLA.

- ✓ There was strong feedback that this Community Workshop had been a valuable shared learning experience, and should both be repeated, and the engagement be sustained in an ongoing 'community of interest'. This was considered to be particularly valuable in helping develop a PSP's work beyond the publication of their Top 10.

 Explore how an ongoing 'community of interest' could work in practice.

- ✓ A recurrent theme during the day, and in feedback afterwards, was the process for development work following publication of a PSP's Top 10. Ideas included providing more advice to PSPs about this 'post-Top 10 phase', engaging with funders, consideration of how research priorities can effectively lead to research questions, and endeavouring to capture all of the work that has gone into a PSP, including the 'unknown knowns' and the 'out-of-scope' questions. For example, the availability of public toilets was a priority issue in the Urinary Incontinence PSP, but it wasn't within scope.

 Consider developing guidance and sharing good practice around the post-Top 10 process.

- ✓ All JLA PSP outputs should be searchable. Further, there could be broader use of the data submitted to JLA PSPs. All PSPs should already provide their spreadsheet of data for publication on the JLA website. It was suggested that the full set of survey submissions should also be provided for secondary analysis, in a way that adheres to data protection guidelines, including anonymised patient narratives. The JLA Guidebook already advises: “Typically, a PSP must make it clear that people’s uncertainties may be published anonymously.” The JLA website could also provide a repository for secondary analysis projects, to avoid duplication and increase shared learning.



Investigate the feasibility of further public sharing of PSP data.