
More than a Top 10:

How James Lind Alliance (JLA) Priority Setting Partnerships (PSPs) transform research, people and organisations

Reflections on maximising the impact of JLA PSPs

From a meeting of the JLA Advisory Group, January 2020

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Introduction

Sally Crowe and Kristina Staley, authors of the [‘More than a Top 10’ report](#), presented their findings from their evaluation of JLA PSPs at a meeting of the JLA Advisory Group on 21 January 2020. The Advisory Group members, made up of 40 people with varying levels of experience of a JLA PSP, reflected on the implications for current and future partnerships, particularly in terms of how they might maximise their impact. This report summarises these discussions, which fell under the following themes:

1. Clarifying the purpose of a PSP at the beginning

Most people who want to start a PSP are hoping that the process will lead to funded research. However, there may be intrinsic value in the process itself, irrespective of the outcome. The collateral benefits as described in the report, are somewhat unpredictable, but worthy of more consideration in the planning. But since the JLA represents a social movement, it will be important to avoid defining their purpose too narrowly and to allow the approach to evolve in an organic way.

Not all PSPs start with a shared understanding amongst all their partners as to the purpose of the PSP, beyond identifying a list of research priorities. Some simply want to get started on the process, focusing on the ‘doing’ rather than the ‘planning’. Such partnerships might benefit from support from the JLA Secretariat to encourage them to pause and reflect on their wider purpose. This represents the first step in planning for the *post*-PSP phase.

Recommendation: The initial assessment of the readiness of a PSP undertaken by the JLA Secretariat’s standard questionnaire could support a broader discussion of purpose and outcomes and encourage planning for the post-prioritisation work. New PSPs could be encouraged to spend more time on this initial thinking.

2. Planning for the post-PSP phase

While PSPs might need to be advised about the need for continued investment of time and resources post-PSP, it was thought important that the messages don’t become off-putting

along the lines of *'This will take the rest of your life!'* Rather than outlining a timeframe for the work, it was suggested that PSPs are informed of the different stages of activity and advised to conserve some energy and funds for the end. *'A JLA PSP not a life sentence, but also not just for Christmas!'*

However, it can be very challenging to make detailed plans for up to 4-5 years in advance. Furthermore, it's not always clear where funding will come from for the post-PSP work. This is especially a problem for PSPs on rare diseases where resources can be scarce. Sometimes it may be easier to make the case for further funding after the PSP outputs have been identified. Any plans need to be flexible enough to be able to respond to the precise nature of the final outputs.

It may be more feasible for PSP partners to simply signal their commitment to working with the Top 10, and to sign up to a principle that *'no question will be left behind.'* This could usefully include the non-prioritised questions that may otherwise be *'left on the cutting room floor'*. The PSP partners need to agree they have a shared accountability for what happens after the PSP.

Recommendation: Share learning amongst PSPs of the different ways they have been able to fund their post-PSP work. This could be in the format of case studies, or more interpersonally with a webinar or as part of the JLA Advisory Group meetings.

3. Disseminating the priorities

Some PSPs reported making assumptions about who and how their Top 10 lists would be disseminated, without allocating tasks and responsibilities to different partners. It seems there would be value in encouraging PSPs to make this explicit from the start in order to *'get their ducks in a row'*. Some stated they would appreciate advice on how to create greater engagement with their priorities, particularly via the general media. Some have experienced difficulties in getting papers published about their Top 10 results.

Recommendations: The JLA Secretariat could host a workshop for PSPs to share good practice in dissemination. Training from communication experts could be offered to PSPs who may not have access to communications expertise.

The NIHR could create a library of PSP results to address difficulties in publishing Top 10's and share this widely across the funding networks.

Guidance could be developed for PSPs on how to disseminate the non-prioritised questions, e.g. NHS Libraries and Knowledge Services are well placed to pick up priorities around health information needs for patients and health professionals and Health Education England could benefit from learning about the concerns patients and carers express about poor quality care.

4. Building relationships with funders

Different PSPs have tried to engage external public funders in the PSP process, but the impact of this is uncertain, as described in the report. It seems that simply attending a Steering Group meeting, attending the final workshop or funding a PSP are not sufficient to establish relationships with external funders that have a significant influence on their funding decisions. It is not clear whether these organisations have an in-depth understanding of the JLA process and its rigour, as well as the value of the outcomes in terms of addressing research waste.

Addressing the cultural barriers to funders working with PSP priorities may be helped through increasing the two-way dialogue between the various organisations involved. For example, funders such as the NIHR could helpfully explain to PSPs how they assess JLA PSP priorities and the remits of the research programmes. Some PSPs start with the belief that NIHR as a public funder is bound to respond to their prioritised questions. Currently it seems as if there are unmet and perhaps unrealistic expectations on all sides that may need reappraisal and resolution.

Historically, for a number of reasons, the NIHR has been seen as the organisation most likely to respond to JLA PSP priorities, but other funders may be more appropriate for many of the questions that currently emerge from PSPs. PSPs could benefit from a greater understanding of what kinds of research other funders would be willing to support.

Recommendations: The JLA Secretariat and others in the JLA community could develop an awareness and educational programme for funders to inform them of the JLA approach, its robustness and its ethos.

The JLA Secretariat could provide more information on its website about the *different* NIHR funding programmes – currently the Guidebook provides an example of working with the NIHR’s Health Technology Assessment (HTA) Programme.

Complementary guidance could usefully inform PSPs about other funders, their interests and the kinds of research they fund.

5. Influencing funders

Some PSPs suggested that the challenges in working with PSP priorities might be resolved by generating outputs in the form of technical research questions (in a PICO format), so that they are easier for funders like NIHR to pick up. On this basis, it was suggested that methodological researchers might be involved earlier in the JLA process to help with the translation process. However, others strongly believed that such an approach would be at complete odds with the principles and values of the JLA and would defeat its purpose to give voice to patients’, carers’ and clinicians’ interests and concerns. *‘A PSP is about the voice of patients and health professionals’.*

It was agreed that one or more people need to take on the ‘champion’ role for a Top 10, who would use their influencing and persuading skills to encourage a response from funders and researchers. The role needs to be developed, but was thought to need people who are:

- Respected in their field
- Free of any political agenda

- Well-networked and operating at a senior level
- Respectful of the need for balance across clinician, carer and patient views
- Good communicators
- Experienced in business, management and /or logistics.

Recommendation: PSPs would benefit from sharing learning on how a post-PSP team can be established, how Steering Group members can be retained and new people with the required skills brought in, perhaps through case studies of successful influencing.

6. Working with the priority questions – the translation process

During a PSP, the Information Specialist and the Steering Group spend considerable time grouping survey responses into overarching, indicative questions. The broad themed outputs then need to be unpacked by funders / researchers, essentially reversing this process and duplicating some of the effort. It may be helpful for the Information Specialist to be more involved in the dialogue with funders / researchers post-PSP.

Many people at the workshop and at other events have commented that they did not know that the survey data from the PSP is made publicly available, although many recognised its potential value in providing depth and nuance to the JLA PSP priorities. Some funders commented that the current format of the data was not useful to them and some were concerned about anonymising the survey responses.

Recommendations: The JLA Secretariat could work with funders to redesign the template for reporting the survey data from JLA PSPs to increase its relevance.

The role of the Information Specialist could be developed to ensure that their approach supports the generation of outputs that are more useful to funders / researchers e.g. by providing their analysis of the categorisation of the survey responses and removing identifying information from the data.

7. Community involvement in the translation process

Several PSPs have taken different approaches to working with their research community to explore priority questions in depth, and to prioritise amongst the multiple research questions that can underpin each one. It's important that these events don't simply repeat of the work of the PSP.

Few of these exercises have been published, since they are often internal to an organisation. Further evaluation could usefully identify which approaches are most successful. One example is the Neuro-oncology PSP Incubator Days where funders and stakeholders work together to develop clinical trial protocols to address their priorities, with a nominated researcher taking the lead on each one. Another is the Eczema PSP which held a translation workshop for their identified priorities. They have been a very successful PSP in terms of impact and this may be another potential model for post Top 10 working.

Recommendation: Further evaluations could be carried out to identify different approaches to wider community involvement in the translation phase.

8. Tracking funding of research that addresses a JLA PSP priority

Tracking which priorities get funded is difficult to do systematically, given the complexity of the research funding system. Asking funders to include a simple tick box in their application forms could help with obtaining a snapshot of how many funding applicants report that they are addressing a priority. A more in-depth question could ask 'Were you influenced by a JLA PSP, and if so how?' Funding panels may be in a position to assess the authenticity of the response, but this raises questions about what criteria the panel would use to make such an assessment.

Recommendation: A group of funders could usefully share their experience of how they assess applications addressing a JLA priority and develop best practice guidance for others.

9. Sharing learning across PSPs

It will be important to update the JLA Guidance taking on board some of the lessons that have emerged in the 'More than a Top 10' report. However, some people commented that the guidance is lengthy and hard to assimilate all at once. '*Guidance can be boring! Need to communicate it in another way with stories and personal connections*'.

Some PSPs were interested in creating opportunities for peer to peer learning by bringing together the staff, patients and carers with relevant experience, particularly to support the post-PSP phase where good practice has yet to be identified.

Recommendations: A shared learning network could be set up for people working post-PSP. Experienced PSPs could mentor new PSPs where they have similar concerns and / or similar contexts that present a challenge.

Stories / case studies could be included in the Guidance to illustrate key learning points.

On the JLA website, the dates of when each PSP finishes could be included, to more clearly identify those that have experience of the post-PSP phase.

More prominence could be given to the work that is done post-PSP on the JLA website.

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