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More than a Top 10:

How James Lind Alliance Priority Setting Partnerships transform research, people and organisations

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The **full report** is available at: https://bit.ly/2mayAw0

About this project

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TwoCan
ASSOCIATES

About TwoCan Associates

TwoCan Associates was established in 2004 and specialises in promoting and supporting patient and public involvement in health and social care research. TwoCan works with NHS and voluntary organisations to help clarify the purpose of involvement, to improve policy and practice, and develop meaningful and effective partnerships. The Director, Dr Kristina Staley, was joint lead on this project. Kristina has worked as an Information Specialist on several JLA PSPs and is familiar with the issues that arise in developing researchable questions from the Top 10's. She carried out an early scoping study in 2008 for the JLA, to explore how public sector research funders make use of research priorities and the potential challenges they face. Further information available at: www.twocanassociates.co.uk

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About Crowe Associates

Crowe Associates, established 20 years ago has a strong record of facilitation, consultation and project management in health and social care organisations and especially in patient and public involvement. Sally Crowe, the joint lead on this project, has partnered with NIHR, INVOLVE, research networks and many voluntary organisations over the years on aspects of public involvement in research. Sally helped establish the JLA in 2003, was responsible for the methodology and supported many PSPs. She has also published one of the few evaluative papers about the research outputs of PSPs and remains curious and engaged in their influence on the research agenda. Further information is available at: www.crowe-associates.co.uk

Executive Summary

Introduction

The James Lind Alliance (JLA) Priority Setting Partnerships (PSPs) enable clinicians, patients and carers to work together to identify and prioritise the questions they would like answered by research. PSPs aim to address the mismatch between what researchers choose to research, and what patients, carers and health professionals actually want to know. PSPs thus provide an important and valuable opportunity for the end users of research to help shape the research agenda.

The aim of this project was to identify the most effective ways for JLA PSP research priorities to influence decisions about what research projects get developed and funded, by evaluating different approaches taken by JLA PSPs to date. The objectives were to:

(a) identify examples of success and develop case studies to explore how researchers and funders were positively influenced in each case

(b) identify challenges and tensions in the use of JLA PSP priorities by researchers and funders and how these have been addressed

(c) explore what practical approaches could be taken to maximise the impact of PSPs, both during the process as well as after identifying a Top 10 list of priority topics

We interviewed 20 people who had experience of working on a JLA PSP, or of working with JLA PSP priorities. The interviews took place between April and May 2019. They included 13 PSP Leads, one manager in a funding organisation, three researchers and three patients. The PSP

Leads came from a variety of organisations including charities, universities and patient groups, some of which also fund research.

The main audience for this report is past, present and future PSPs. We hope the lessons learnt will help PSPs with the work that happens after the JLA process has concluded, and could usefully inform future evaluations.

Key lessons and conclusions

Even with the small number of PSPs involved in this project, we have revealed a rich and complex picture of the outcomes and impacts of JLA PSPs which go beyond simply funding research, and broaden the definition of what success looks like. Taking part in a JLA PSP can have a dramatic impact on the individuals involved, both professionally and personally. For example, it has enabled patients to expand and enhance their involvement in other parts of the research system, improved the reputations and status of researchers, and changed clinicians' clinical practice. Organisations that lead a JLA PSP report major cultural shifts that result in new partnerships with other organisations, promote greater internal collaboration across departments and/or extend and enhance patient and public involvement in their work. In charities that fund research, the experience has changed relationships between funders and researchers, with less emphasis placed on competition and greater emphasis on working together to achieve a common goal. These 'collateral benefits' come in addition to a shift in research funding towards the issues that matter most to patients, carers and healthcare professionals.

The context for each PSP is hugely significant, for example whether the research area is contested, whether an active research community already exists and whether considerable research on a topic has already been completed. The starting point of the PSP, what it aims to achieve and the specific individuals and organisations involved – these all shape the process and outcomes, making it difficult to draw general conclusions about 'how to succeed'. With this caveat, we have identified some of the key lessons for PSPs, recognising that these will not be universal. We conclude it is important for PSPs to:

- Plan for the end of the PSP at the beginning of the project, in particular to clarify who owns the outputs, who will make decisions about how they are used, who will be accountable for what happens next and how the follow-up work will be resourced

- Develop dissemination plans to reflect the PSP's strategic goals, which may go beyond funding research and reach audiences beyond funders and researchers

- Make greater strategic use of patients, carers, clinicians and researchers in promoting the JLA priorities through their own networks, rather than focusing solely on publications

- Work with funders after the PSP to shape their research agenda, recognising that they may not believe it is their responsibility to respond to the priorities – this influencing work requires people with the right skills and experience, often senior leaders within organisations

- Ensure continued involvement of clinicians, patients and carers in the translation of JLA PSP priorities into themed calls and research projects, so that the spirit of the original questions are maintained

- Carry out foundation work to build researchers' capacity to respond, promoting collective thinking on an issue, as well as identifying barriers to the research and addressing them

- Collect information about research that has been completed in response to JLA PSP priorities and make it publicly available

- Assess the wider impacts of the JLA process and share these amongst all stakeholders to promote a deeper understanding of how PSPs work and the value of JLA PSP priorities

This evaluation has also begun to identify factors within the wider research system that limit the influence of JLA PSP priorities. These include the values held by funders and researchers, and the dominant culture within research organisations. This may mean that funders and researchers use the JLA PSP priorities to endorse and legitimise what they have already planned to do, rather than making significant change. It may be beyond the power of individual PSPs to bring about the wholesale cultural shift required to genuinely change the national research agenda in favour of patients, carers and clinicians' priorities. Addressing deeply embedded beliefs and values is likely to require action from a wide range of stakeholders.

For this reason, many of the lessons contained in this report could be helpfully addressed by others beyond those immediately involved in a JLA PSP, including the JLA Secretariat, JLA Advisers, funders and

researchers. We recommend that the findings form the basis for future conversations, enabling these stakeholders to work together to develop their views on how best to respond. We suggest that some of the questions that could be usefully addressed include:

- **Planning**: If the work of promoting and influencing others at the end of a PSP needs to be properly planned and resourced at the beginning, is there a role for the JLA Secretariat to support this planning? What level of resourcing should be recommended? And where should this resource come from?

- **Disseminating and influencing**: If simply disseminating the priorities is not always sufficient to promote their uptake by researchers and funders, what can be learnt from implementation science about how to encourage others to change their behaviour in light of new evidence?

- **Responding by funding relevant research**: When assessing a research project that aims to address a JLA PSP priority, how can this be judged in a practical and meaningful way? What should funders, grant reviewers and members of funding panels be asking and looking for?

- **Responding in ways other than through research**: How can non-research questions be used for the benefit of patients, carers and clinicians i.e. to meet their information needs and to improve healthcare policy and practice? Which stakeholders need to be involved in

this work and how can it be resourced?

- **Translating**: What are the tasks involved in the translation step from JLA PSP priority to research question or themed call? Who needs to be involved? What support and information do they need to do the tasks well?

- **Evaluating**: What are practical and meaningful ways of capturing whether new research addresses a JLA PSP priority? How can the scale and nature of the change to a portfolio be described? How can the change in the nature of individual research projects be captured? How can the wider impacts of the JLA process be captured?

- **Transforming research organisations**: If the goal is to transform the research culture in such a way that it better reflects the needs and interests of the end-users, what are the implications for the way the research organisations currently function, in terms of what they do and how they do it? How do they need to change to be able to respond in a meaningful way to the JLA PSP priorities?

- **Transforming people**: How can individuals' contributions to the process be better recognised and rewarded within the research system? How can the skills and experience that individuals gain through the JLA process be put to better use in the ongoing work and in other context