



**How can you maximise the impact of your JLA PSP?**

**A proposal from TwoCan Associates**

**& Crowe Associates**

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**1. Introduction**

1.1 The James Lind Alliance (JLA) [Priority Setting Partnerships (PSPs)](http://www.jla.nihr.ac.uk/priority-setting-partnerships/) enable clinicians, patients and carers to work together to identify and prioritise the questions they would like answered by research. These shared interests of patients, carers and clinicians have often been overlooked in clinical research. As a result the questions patients, carers and clinicians consider important have often been neglected and many areas of potentially important research have not been addressed (1). Even when researchers do address questions of importance to patients and clinicians, they often fail to provide answers that are useful in practice. JLA PSPs aim to address this mismatch between what researchers choose to research, and the practical information that is needed day-to-day by patients and health professionals. The PSPs thus provide an important and valuable opportunity for patients and clinicians to help shape the health research agenda (2).

1.2 The JLA method, as described in the [JLA Guidebook](http://www.jla.nihr.ac.uk/jla-guidebook/) (3), is now well-established and over 50 PSPs had taken place or were underway in August 2018. The PSP process itself comes to an end at the point at which a top ten list of research priorities has been identified. The partner organisations involved in each PSP then make great efforts to publicise the results amongst UK and sometimes international audiences. They aim to encourage researchers to develop projects that address the top priorities, and to encourage research funders to fund this work.

1.3 Based on informal reports, different JLA PSPs have successfully influenced researchers and funders, leading to research projects that have targeted a priority topic. Such approaches have included:

* Involving funders as partners in the PSP to shape decisions about the scope
* Involving funders as observers of different parts of the JLA method
* Patient organisations who fund research using priority topics to make calls for proposals or to influence funding decisions
* Funders commissioning research to address a JLA priority topic

1.4 Informal reports and conversations have also identified some challenges in making use of the JLA priorities, including:

* Some top tens include very broad questions rather than specific research questions – how should questions be identified and prioritised within these broad topics?
* Translating patient/ carer/ clinician questions into technical research questions – does this change the focus or emphasis of the original question?
* How to prioritise across different PSPs that are all identifying different priorities – are there common questions that might be considered an even higher priority?

1.5 The aim of this project is to determine what are the most effective ways for JLA PSP research priorities to influence decisions about what research projects/ programmes get developed and funded, by carrying out an in-depth evaluation of the different approaches that have been taken to date. This will involve:

(a) Identifying examples of success and developing case studies to explore precisely how researchers and funders were positively influenced in each case

(b) Identifying any barriers to the use of JLA research priorities by researchers and funders and exploring how such barriers can be overcome

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

**2. About TwoCan Associates & Crowe Associates**

2.1 TwoCan Associates was established in 2004 and specialises in promoting and supporting patient and public involvement in health and social care research, working 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, will jointly lead on this project. She 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 tens. She carried out an early scoping study in 2008 for the JLA (4), to explore how public sector research funders make use of research priorities and is familiar with the potential challenges they face. Further information available at: [www.twocanassociates.co.uk](http://www.twocanassociates.co.uk)

2.2Crowe 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 James Lind Alliance in the 2003 and was responsible for the methodology and supported many PSPs over the years. 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 (1). Further information available at: [www.crowe-associates.co.uk](http://www.crowe-associates.co.uk)

**3. Proposed approach**

3.1 The project will involve the following five stages:

* 1. Initial preparation and consultation
  2. Planning the case studies and interviews – Advisory Group Meeting
  3. Conducting interviews and analysing the findings - draft report
  4. Developing recommendations – Advisory Group meeting
  5. Final report

These will now be discussed in turn, followed by an outline of how patients, carers and health professionals will be involved and how best practice will be followed in terms of research governance.

**(a) Initial preparation and consultation**

3.2 We will carry out an initial consultation of the key stakeholders in this project, JLA advisers and managers, representatives of funding organisations, representatives from previous JLA PSPs to include clinicians, patients and carers, staff from patient organisations and clinical researchers. We will ask these informants to identify potential case studies of where JLA PSPs have successfully influenced researchers and/or funders as well as identifying people who could be interviewed for their perspectives on the challenges in making use of JLA research priorities in Stage (c).

3.3 We will invite a group of approx. 10-14 people to form an Advisory Group. This will include representatives of all the stakeholders in the project (as listed above) and will meet twice, as discussed below. The Advisory Group will play an important role in shaping the project and developing the final recommendations to ensure they are practical and relevant to past and future PSPs.

**(b) Planning the case studies and interviews – Advisory Group Meeting**

3.4 At the end of stage (a), we will have produced a *draft* list of potential case studies that illustrate success stories, a *draft* list of potential interviewees to ask about challenges and a series of *draft* interview schedules for different categories of interviewee. We anticipate the questions will ask interviewees to reflect on their experience of working with JLA research priorities to influence researchers/ funders, and to answer questions about what worked well, what could be improved, what they perceive as the challenges as well as how these might be overcome.

3.5 Advisory Group members will provide their perspective on which case studies and which interviewees should be short-listed for inclusion in the project. They will also be asked to comment on the interview schedules, so as to ensure their interests and concerns are reflected in the questions that are asked.

**(c) Conducting interviews, analysing the findings and producing a draft report**

3.6 At the end of stage (b), we will have a final list of interviewees and a series of semi-structured interview schedules for different categories of interviewee. The interviews are expected to last 45-60 mins. We anticipate the majority to be carried out on the phone, although some might be carried out face-to-face.

3.7 We are highly experienced in making our interviewees feel at ease, quickly establishing trust, and avoiding making people feel that they are being judged. In our initial conversations with interviewees, we will emphasise our independence and professionalism around issues of confidentiality and anonymity, which we hope will encourage people to open and honest in their views.

3.8 With the interviewee’s permission, all interviews will be recorded and transcribed. The transcripts will be analysed by KS and other project partners, using thematic analysis, which involves developing themes from the data (rather than being shaped by an existing theory). The recordings will be deleted at the end of the project.

3.9 We will produce a draft report that outlines the findings from the interviews. This will be sent to all interviewees for comment, and to check they are happy with the way their quotes have been used. We will ask interviewees to choose whether they would like any quotes from their interview to be attributed to them personally, or more generally (e.g. as a research funder) or whether they would prefer to be completely anonymous. We will also give the interviewees the option as to whether they would like to be acknowledged by name in the final report.

**(d) Developing recommendations – Advisory Group meeting**

3.10 The findings from Stage (c) will be presented and discussed at the second Advisory Group meeting. Other stakeholders may be invited to attend this meeting if relevant and appropriate. The aim will be to develop a series of practical recommendations that will benefit all stakeholders to support their continued partnership working to ensure JLA research priorities can genuinely influence the research agenda.

**(e) Final report**

3.11 We will produce a final report in plain English that draws together the findings from the interviews and discussions with the Advisory Group and other stakeholders. It will include:

* An executive summary
* A description of the methods used in the evaluation and the ways that the various stakeholders have been involved
* A series of case studies where JLA PSPs have successfully influenced funders/ researchers – the lessons learnt and implications for others
* A description of the potential challenges to working with JLA priorities and suggestions as to how these might be overcome
* A list of recommendations for stakeholders involved in past and future PSPs as to how they might maximise the impact of JLA PSPs
* An acknowledgment of the input of all of the people who have been involved in this evaluation

3.13 We will also produce a journal article to share the findings with a wider audience, including others working with patients, carers and professionals to identify research priorities.

***Our approach to working with patients, carers and clinicians***

3.14 The project Advisory Group will include at least two patients/ carers and clinicians with experience of working on a JLA PSP. Throughout the evaluation, we will seek to ensure that:

* We are mindful of, and our work is informed by patient, carer and clinician perspectives as well as those of other stakeholders
* Patients, carers and clinicians are partners in shaping the development of the evaluation
* The skills, knowledge and experience of patients, carers and clinicians are valued and respected as well as those of other stakeholders
* Everyone who gets involved will be informed about how their involvement has made a difference
* Patients and carers are not out of pocket for their involvement in this project

***Our approach to research governance***

3.13 This project does not require ethical approval according to current National Research Ethics Service guidelines, as it takes the form of an evaluation rather than research. However, we will still ensure that we follow best practice by:

* providing a clear explanation of what the project is about before people decide whether to participate
* conducting interviews at a time and place to suit interviewees
* getting permission from interviewees to record interviews, and agreeing what will happen to the recordings at the end of the project
* discussing issues of confidentiality and anonymity before starting each interview
* asking interviewees to check early drafts of the final report to check they are happy with the interpretation of their quotes
* providing feedback on the findings/outcomes to everyone who took part

**References**

1. Crowe S, Fenton M, Hall M, Cowan K and Chalmers I. (2015) Patients’, clinicians’ and the research communities’ priorities for treatment research: there is an important mismatch. *Research Involvement and Engagement*, 1:2
2. James Lind Alliance Priority Setting Partnerships (JLA PSPs): [www.jla.nihr.ac.uk/about-the-james-lind-alliance/about-psps.htm](http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/about-psps.htm) (accessed 30 July 2018)
3. JLA Guidebook [www.jla.nihr.ac.uk/jla-guidebook/](http://www.jla.nihr.ac.uk/jla-guidebook/) (accessed 30 July 2018)
4. TwoCan Associates (2008) Scoping research priority setting, and the presence of patient and public involvement, with UK clinical research organisations and funders [www.jla.nihr.ac.uk/news-and-publications/downloads/Annual%20Report%202008-10/Annexe-13-2008-10-ScopingResearchPrioritySetting-TwoCanReportSummary.pdf](http://www.jla.nihr.ac.uk/news-and-publications/downloads/Annual%20Report%202008-10/Annexe-13-2008-10-ScopingResearchPrioritySetting-TwoCanReportSummary.pdf) (accessed 30 July 2018)

**4. Timetable and Budget**

An estimate of the costs for this project are listed below. Our hope is that the partners in this project may be able to provide a venue for meetings and that the paid professionals involved in the Advisory Group will be able to cover their costs for attending meetings. All other costs will need to be covered by the project budget.

|  |  |  |  |
| --- | --- | --- | --- |
| **Date** | **Activity** | **No. of Days** | **Estimated costs** |
| **Month 1** | **Stage 1: Initial Preparation**  Recruitment of Advisory Group Members  Interviews with key informants and preparation of papers for the first Advisory Group meeting | 2 researcher  4 researcher |  |
| **Month 2** | **Stage 2: Planning the case studies and interviews – Advisory Group Meeting**  Organisation of the meeting  Advisory Group meeting  Attending meeting and finalising lists and interview questions | 1.5 admin  2 facilitator  2 researcher | Travel for two patients/ carers, facilitator and researcher  Fees for two patients/ carers |
| **Months 3 – 4** | **Stage 3: Conducting interviews and analysing the findings & draft report**  Telephone interviews with 20 interviewees – each 45-60 mins long, recorded and transcribed – 16 telephone, 4 face to face  Review of documentation from previous PSPs – e.g. to identify common questions across all the top tens  Analysis & draft final report | 8 researcher  5 admin  5 researcher  10 researcher | Travel to 4 interviews |
| **Month 5** | **Stage 4: Advisory Group meeting**  Organisation of the meeting  Advisory Group meeting  Plan and attend Advisory Group meeting | 1.5 admin  2 facilitator  2 researcher | Travel for two patients/ carers, facilitator and researcher  Fees for two patients/ carers |
| **Month 6** | **Stage 5: Final report**  Revisions to report following Advisory Group meeting  Dissemination – blogposts, newsletter articles etc.  Journal article | 1 researcher  2 researcher  4 researcher |  |
|  | **Publishing charges for open access** | £1,500 |  |
|  | **Total** | **£26,500** |  |