

# **James Lind Alliance (JLA) Symposium 23 June 2015**

## **Learning from JLA Evaluations - Shaping Future JLA Methods**

**Symposium Report—prepared by Sally Crowe, Crowe Associates,  
with the JLA team at NETSCC, JLA Advisers and speakers/  
contributors to the day**



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The [James Lind Alliance \(JLA\)](#) is a non-profit making initiative established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 uncertainties, or ‘unanswered questions’ about the effects of treatment.

Since April 2013, the secretariat of the JLA has been hosted by the National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre ([NETSCC](#)). This work includes recruiting and training JLA Advisers, coordinating PSPs, looking after central JLA communications and liaising with other parts of the [National Institute for Health Research](#). JLA PSPs are characterised by following the method set out in the [JLA Guidebook](#) and are facilitated by one of a small team of NETSCC-approved [JLA Advisers](#).

**Acronyms used in this report:**

**JLA** - James Lind Alliance

**PSP** - Priority Setting Partnership

**NIHR** - National Institute for Health Research

**NETSCC** - National Institute for Health Research, Evaluation, Trials and Studies  
Coordinating Centre

**PPI** - Public and Patient Involvement

**PICO** - structure for interventional research questions— **P**opulation, **I**ntervention, **C**omparison  
and **O**utcome

**NICE** - National Institute for Health and Care Excellence

## 1. Summary

This one-day event marking almost 10 years of James Lind Alliance (JLA) Priority Setting Partnership (PSP) activity was an important 'pit stop' in its evolution. With 31 completed partnerships, 23 ongoing, and more in preparation, there is a growing body of work to explore and learn from. Over 40 people met to hear from those who have evaluated JLA activity, process and impact, debate the key issues and suggest important evaluation questions. The selection of evaluations provided much food for thought, addressing issues such as the relative and perceived importance of patient-generated questions vs. those from clinicians, how partnerships interact and make key methodological decisions, the best and most cost-effective ways of collecting questions of uncertainty, and finally whether it is feasible to 'do JLA in a day'. Not surprisingly with JLA enthusiasts and sceptics present a lively debate was generated. Some of the key issues were methodological. Others were more strategic, commenting on research culture and the impact of research on patient and clinical benefit.

Making comparisons to other forms of decision making also proved insightful - in partnerships, what motivates people to get involved, who holds the real power in decision making, how much do we really reflect on what has been achieved, and what has helped and/or hindered PSP outcomes?

Two discussion groups explored the JLA partnership process in more detail from top to tail, resulting in many evaluation questions but also suggestions for improvements in JLA guidance and information. One group tackled the issues of who gets involved in JLA PSPs and whether we support patients and the public enough in this? Finally a more internationally focussed group addressed the challenges of managing a process and brand that has 'gone global' and ensuring that the all-important values of the JLA (accessibility, inclusiveness, transparency and evidence-based) are upheld. This group also explored new avenues for the JLA process in public health, health inequalities and regional PSPs that address local research issues using existing networks and partnerships.

There were, as you would expect, some themes that cropped up throughout the day and across the small groups, for example:

- capturing learning from and across PSP activity more effectively
- increasing and improving guidance for those undertaking a PSP whilst not stifling innovation and creativity
- establishing the most cost-effective methods at each stage of the PSP process, such as methods for prioritisation
- the value of the final face-to-face workshop (as distinct from using online voting only)
- whether or not the size of the consultation response from patients and clinicians matters to the overall outcome and credibility of the PSP.

The symposium concluded with some words from NETSCC via Matt Westmore (Director of Finance and Strategy), who reiterated NETSCC's commitment to the JLA and to providing the Infrastructure for PSPs to flourish along with being a custodian of the values, method and brand. We thank all of the participants for giving their time, energy and thoughtfulness to what is a dynamic and challenging area of research priority setting process development.

## 2. Overview of symposium

This symposium arose out of conversations between the JLA team based at NETSCC, JLA Advisers and researchers involved in JLA PSPs. It was evident that there was considerable interest in evaluation and projects underway that sought to evaluate different aspects of JLA methods and impact on the research community. The symposium would provide an opportunity to hear about these evaluations and discuss their impact.

The symposium objectives were to:

1. Share experiences of JLA evaluation activity in PSP methods, and outcomes
2. Consider the evaluations presented, in light of JLA methods development
3. Establish the main issues identified at the symposium for future research and evaluation of JLA prioritisation and engagement.

Ideally, all of the JLA PSPs would have taken part but there was limited resource and capacity, so not all PSPs were represented at the symposium. However, those present included an eclectic mix of participants of past and present JLA PSPs including clinical, charity, patient and public, carer, health professional and researcher perspectives; methodologists interested in research priority setting and participative research, influencers in the research community, JLA Advisers and NETSCC staff from within the JLA team and across the organisation. The event took place in central London on 23rd June 2015. The symposium programme and participant list are in Appendix 7.2 and 7.3.

The event produced a great deal of information in the form of participant questions and issues on Post it notes, flipchart notes from the small groups, notes taken in the small and large group discussions by NETSCC staff and the parallel Twitter discussions. In order to prepare this report, themes from this data were developed, rather than a literal reporting of all that was discussed. Items on Post it notes that were not used in the small group discussions are transcribed and themed in Appendix 7.1. Quotes throughout the text represent either written or discussion comments by symposium participants.

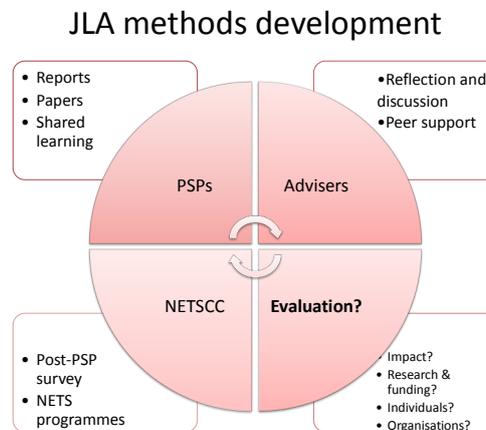
### 3. Overview of presentations

**Sally Crowe** introduced the day and asked the audience to keep their eyes and ears open to new ideas and challenges to JLA methods and impact. She quoted several sources in the literature suggesting that the need for evaluation of all research priority setting was overdue and that the JLA should contribute to this body of knowledge.

*"Priority setting is only as good as the health improvements that result from it."*

**Katherine Cowan, Senior JLA Adviser**, gave an overview of the JLA since its inception. This included the development of its methods and underpinning values and the scope of its activity. She demonstrated the diversity of issues addressed by partnerships and the exportation of the JLA approach across the world. Katherine also clarified how JLA PSP activity is currently reviewed within the NETSCC structure (slide 1), but highlighted the need for more external and structured evaluations.

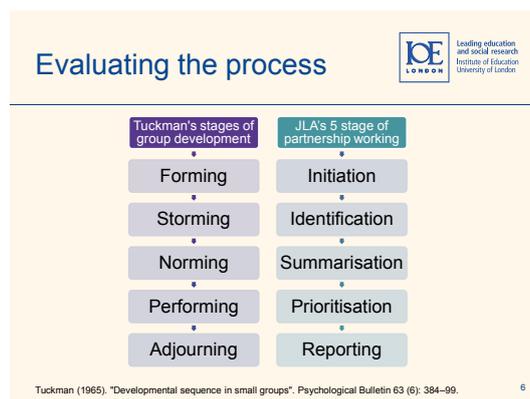
#### Slide 1: Overview of how JLA methods are developed and opportunities for evaluation:



**Rosamund Snow and Joanna Crocker**, both researchers from **Oxford University**, offered a critical view of an essential step of the [Type 1 Diabetes](#) PSP. The early decisions about the scope of the PSP and the data inclusion and exclusion criteria and processes can be crucial to the eventual outcome. They showed, with post-PSP evaluation of the original gathered uncertainties, that patient and carer generated data was more likely to be considered out of scope than that from professionals. This is an important finding when the JLA principle of equity of voice in a partnership is highly valued. They suggested several steps for subsequent PSPs to avoid this outcome, such as having patients and carers involved in early decision making within the PSP Steering Group.

**Seilin Uhm** from the **Social Science Research Unit** at the Institute of Education discussed early findings from her PhD which appraised how people within the JLA partnership interact and make decisions. The use of Tuckmann's stages of group development (forming, norming, storming, performing and adjourning) as a comparator really helped people understand and compare the development of a PSP over time, see slide 2.

## Slide 2: Tuckmann's model of group development compared to a JLA PSP group development



Additionally, Seilin shared post-PSP evaluation of the complex breakdown of different voting behaviours within the [Preterm Birth PSP](#). Using a technicolour approach she was able to show that despite areas of consensus in the interim voting stage there were also distinct differences between service users and clinicians. Service users were more interested in antenatal questions compared with clinicians who were more interested in post-birth questions. This has implications for PSPs in their final stages - how much do we embrace these differences or strive for consensus?

**Sandra Regan and Sophie Petit-Zeman** from the **Oxford Biomedical Research Centre** brought us right back down to earth with the results of an evaluation that compared different ways of gathering uncertainties from patients and carers in the [Hip and Knee Replacement PSP](#). Clinicians' uncertainties were also gathered via survey and focus group, but not included in the analysis. The methods compared included an online and postal survey, discussion groups, and gathering uncertainties from existing qualitative research as part of [HealthTalk](#) (an online resource of experiences of health care). Comparisons were made by coverage of issues (survey gets the most) and cost (survey is the cheapest); however other methods delivered a depth of question (discussion groups) and unique insights (HealthTalk). Each PSP makes their own decisions about data collection, and this study provided useful analysis to consider.

Finally, **Allison Tong** from the **University of Sydney**, Australia, challenged the whole room with an account of a 'one-day' JLA. Many in the research community discuss and ask about the time and resources needed to produce a Top 10, however there are few examples of one-day processes to make comparisons with the 'usual' JLA PSP approach. Allison described the large one-day workshop which focussed on research priorities in Chronic Kidney Disease. The challenges of large groups of diverse participants, real-time data analysis and getting political 'buy in' to the priorities post-workshop were outlined and the presentation generated a lot of interest in subsequent discussions.

Abstracts of all these presentations are available in **Appendix 7.4**

#### 4. Discussion associated with presentations

After clarifications and questions of the presenters, **Simon Denegri** and **Mary Madden** offered perspectives on each of the presentations, stimulating further discussion.

The wide-ranging debate included acceptance that there is a need to extend impact measurements (beyond the uptake of research priorities) but also to capture the different perspectives as they are experienced across conditions and people involved in PSPs.

The presentation from Rosamund and Joanne triggered a debate about the importance of scoping the PSP but also having a plan for the excluded questions - either because they are not uncertainties (but do suggest an information gap) or because they are out of scope (but may be interesting nonetheless). Transparent reporting of this stage was also thought to be advantageous. This raised the issue of how to handle non-interventional questions (the original JLA method was developed to handle treatment/interventional research only).

Using PICO in 'cause' questions is inappropriate and for some PSPs (e.g. Parkinson's) there are not many interventional uncertainties to focus on.

*"We need a broad understanding of intervention such as information provision/advice, social interventions, clinicians as interventions, and public health interventions."*

Does the JLA need to revisit its definition of uncertainty when working with non-interventional questions? We do know from existing PSPs that cause and prognosis questions are very popular, and relevant to patient and clinical communities.

Discussions about research question structure also generated a discussion about how JLA PSPs can represent outcome data better. Explicit outcomes help make better research questions, however most PSP surveys generate information about interventions and populations but are less likely to generate insights into outcomes and hardly ever comparators. So a challenge for PSPs is how much effort they put into collecting this information.

Seilin's observations about the day-to-day working of PSPs highlighted the challenges of a diverse group of people steering an often complex process, for many different reasons! It was suggested that the Tuckmann model is a linear one and does not necessarily reflect the messy aspects of involvement! Partnerships need to be reflective about their work and relationships, and their learning needs to be passed on to future PSPs. A participant also suggested that the more diverse a partnership, the greater it's potential reach in terms of the inclusivity of the process, but also the impact of the research priorities.

Participants mulled over the different merits of how we collect uncertainties. Clearly there aren't HealthTalk modules in every disease area so that option isn't always open, and surveys seem to offer 'more bang for your buck'. We acknowledged that asking people to tell us their questions is challenging and we need to continue to make it as easy as possible.

Allison's presentation set the hares running about the sometimes burdensome feel of a JLA PSP. It's a lot of work. Are there ways that we can make it simpler? However there were defendants of the current JLA approach and concerns about who will pay attention to a one-day affair?

*"Does a survey give you 'the numbers' therefore PSP credibility?"*

There was a suggestion that a 'JLA in a day' can provide a solid base from which to expand and develop ideas and further refine research questions. The traditional JLA PSP approach as well as a Top 10 may yield increased and strengthened collaborations for research, participant learning and development, learning about research processes and group working, and increased profile of the research gaps and the condition itself (there have been JLA PSPs on relatively rare conditions).

Finally, we discussed the impact of a JLA PSP on the existing research culture and funding patterns in that area. There has been mixed success in this regard. Sally mentioned a paper to be published about the ongoing mismatch between important research questions (as defined by the first 14 JLA PSP Top 10s) and clinical trials that are funded in the same time frame. See <http://blogs.biomedcentral.com/on-medicine/2015/06/25/patients-clinicians-research-priorities-really-matter/>

She suggested that there is a need for greater impact and reach of JLA priorities. One participant suggested that involving (non-clinical) researchers in JLA PSPs may help translation and uptake of research priorities. There is also the question of 'who moves most' - a challenge from the floor about how much research funders should meet JLA PSP research priorities and how much JLA PSPs should change their outputs to match the needs of the research funding community.

*"Need a better alignment between JLA outputs and what researchers want to hear."*

*"We need funders to align themselves to PSPs rather than the other way around."*

Simon Denegri compared the JLA with *Strictly Come Dancing* - he wondered how the JLA works with a scientific audience that judges the JLA Top 10s and sometimes find them wanting, and changing the culture of "it's about the best science" to one of good science and relevance?

*"How long can we keep the Top 10 on the Strictly Come Dancing dance floor?"*

Finally **Sandy Oliver** got in a metaphorical helicopter and hovered above the JLA presenting the symposium audience with some new ideas taken from her involvement in a PSP, but also from her review of the literature and work with NICE Committees. Firstly she acknowledged the differences in priorities across groups - and made a radical suggestion!

*"Why not focus on what service users want and what clinicians want, even if they are not the same?"*

Some PSPs pay close attention to the provenance of their research uncertainties. The [Eczema PSP](#) did indeed separate the important questions from patients and carers, those from clinicians and those that were shared, totalling 14 priorities in all.

Sandy then went on to describe some of the evidence related to group working, size, diversity of opinion and the role of IT platforms to support group working. She explicitly acknowledged the role of group chairs and facilitators, and power dynamics within groups. She finished with an evaluation 'shopping list' of items we would like to understand better such as effective training and development for full participation in research priority setting groups.

## 5. Key points from small discussion groups

Following a lunch break, symposium participants re-focussed the discussions in smaller facilitated groups (thanks to JLA facilitators Katherine Cowan, Sheela Upadhyaya, Richard Morley and David Crowe), each with specific topics to reflect on, and with reference to the morning's evaluation presentations. The planning team were particularly interested in the implications for JLA methods and impact evaluations arising from the discussions, however as expected some of the points concern information and guidance provided by the JLA.

### General comments that ranged across all four groups:

**JLA 'brand':** a real sense in the symposium that the JLA brand is a good one and has the hallmark of a job well done. The JLA values underpin this, as well as the attention to detail by PSPs.

**Guidance for PSPs:** General understanding that the JLA Guidebook is not prescriptive. It needs options and examples from each PSP stage, so that users can make informed choices to suit their needs and available resources. Generally PSP participants seem to want more information and guidance, but without limiting innovation.

**Capturing PSP learning:** with such a large cohort of PSPs it seems sensible to find a way to capture learning and challenges so that this can be shared more widely, through the JLA Guidebook but also in more dynamic ways, e.g. Action Learning Sets (people meeting regularly to reflect on progress across a shared area of interest and helping to solve each other's problems) or using online platforms.

**Does size matter?:** How efficient is it to generate thousands of responses to JLA surveys? Should you judge a PSP on the number of responses you have received? Is it unhelpful for PSPs to worry if they haven't generated enough interest and could therefore be seen as less valid? This theme was often related to the relative representativeness of patient and clinical participation in the JLA process.

**Roles within PSPs:** Many people involved in PSPs wear multiple 'hats' (such as service user, researcher) and may also develop in roles as the PSP progresses. Quite a lot of discussion took place about the merits (or not) of involving researchers who are not active clinicians (e.g. clinical trialists, medical sociologists, systematic reviewers) in the process.

**PSP outputs:** Is the main job of the PSP to produce the most important, or the most interesting questions? Is it the larger scale 'thematic' questions or the more specific PICO questions that interest researchers and funders? We seem to be expecting more and more of PSPs and the JLA, stretching it into a place where it was never intended to be.

**Interpretation of JLA methods:** How much does it matter that PSPs deviate and interpret the core JLA approach? What is the role of the JLA values - are these prominent enough?

**Post PSP:** How do we keep the momentum and achievements of the PSP ongoing? Participants were interested in understanding how to create networks (or plug into existing ones) to spread the word about the results. Managing expectations of PSP participants is important as they can be disappointed when their questions are not taken up for research. Getting PSP priorities funded is the most important next step of a PSP and a wide range of views were shared on this including should all JLA PSP respondents be encouraged to become research lobbyists?

**UK DUETs:** UK DUETs serves one purpose, but is it the purpose that JLA PSPs need? More information about who uses UK DUETs would be helpful to PSPs.

**JLA PSP conflicts:** Are PSPs in competition with each other for research funding? Is there a danger of 'flooding' the market of research funders? However if these priorities are not being funded then this argument is less compelling.

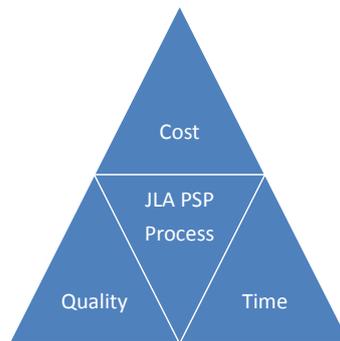
## Specific group discussion points:

### 5.1 JLA Process - start to finish

Many of the discussions and comments on Post it notes concern the relationship between cost, time and quality of process for PSPs, and the inherent tensions within this triangle (slide 3).

Additionally PSPs seem to want more guidance on just about everything (scoping, project management, costs, data management etc), benchmarking information about the desirable size of datasets and response rates, and how detailed JLA PSP priorities should be.

### Slide 3: Relationship between cost, time and quality within a JLA PSP



#### 5.1.1. Gathering uncertainties and data management

##### What could we change in the short term?

- Develop a decision tree or framework (based on PSP experience) about how and when to start PICO activity for interventional questions.
- Getting data into the exact format for UK DUETs is very difficult for some PSPs. Guidance on the right process and skills needed to achieve it would help.
- The Guidebook could have more information and signposting to existing sources of patient/clinical experience (e.g. online collections of patient experiences) to either inform discussions or even provide uncertainties.

##### What could we change in the longer term?

- Guidance needed on what PSPs should do with questions about local provision/access of treatment and care (aka post code lottery)? These are common across PSPs. Are they legitimate research questions for a JLA process, or not?
- Gain consensus about guidance for aspirations for representativeness of the community of interest (patients, public and health professionals).

##### What needs more formal evaluation?

- Could assessing uncertainty (via Systematic Reviews, NICE Guidance etc) be an opportunity to engage with the research community?
- Are we losing the meaning of individual questions when we try to represent them in one indicative question? How much do JLA uncertainties need to be 'research questions' and what is the role of researchers in this?

- What would be the value of having one place where all the outputs of JLA PSPs (including the Top 10) could be hosted?
- What are the implications of setting priorities within narrow or broad scopes, and using subsets?
- Are there more cost-effective methods for collecting uncertainties?
- Could awareness meetings or 'JLA in a day' be a starter event to scope and gather themes for uncertainties?
- Could focus groups help define the scope of a PSP or identify thematic areas to explore via survey?

### 5.1.2. Prioritisation (interim and final)

#### What could we change in the short term?

- Guidebook being more transparent about inclusion and exclusion criteria for PSPs to consider when making scoping decisions (*e.g. limiting the PSP activity to treatment and therapeutic uncertainties*). Having a plan for excluded questions if there are resources available, and if not highlighting them for others to consider.

#### What could we change in the longer term?

- Gathering information about how PSPs use criteria and make decisions to reduce the starting list of questions (*sometimes called the long list*) into an interim voting list, encouraging PSPs to be more transparent about this phase (*e.g. describing the process and decisions made in published accounts of the PSP*).
- Gathering more information about how PSPs undertake interim prioritisation? (*We know that a variety of methods are being used such as participants choosing their personal Top 10 or ranking all research questions using a scale. We don't know why PSPs choose their method, and which is best*).

#### What needs more formal evaluation?

- Explore the value of weighting of responses in prioritisation processes.
- Can the final prioritisation be done virtually? *Can we be explicit about the value that the final workshop adds to the process? NB The [Eczema PSP](#) didn't have a final workshop - they took the votes as final and had a research development workshop for the Top 14 questions.*
- What is the role of the 'lone wolf' questions (i.e. one question from one person)? *These are often asking a similar question to a group (indicative) question but have enough difference to make it a separate question.*

### 5.1.3. Dissemination and funding of priorities

#### What could we change in the short term

- Guidance and resources on creating a PSP research priorities dissemination plan; and a hit list of research funders that might be interested in the priorities.
- PSPs consider a specific engagement process with researchers to review plans for dissemination, and how priorities are presented to research community.
- NETSCC (JLA) need to be clearer that they do not normally fund PSPs, a common misunderstanding.
- NETSCC needs to provide clearer messages about its role in funding PSP priorities and clear up misconceptions about it funding all JLA outputs.

- The issue of publication was raised, with a participant mentioning a JLA PSP related journal article which had been rejected because the PSP did not have ethics approval. There is guidance on the INVOLVE website which makes it clear that ethics approval is not necessarily needed for a PSP type research process. *“Ethical approval is not needed for the active involvement element of the research, (even when people are recruited via the NHS), where people are involved in planning or advising on research e.g. helping to develop a protocol, questionnaire or information sheet, member of advisory group, or co-applicant.”* This information needs to be made available in the Guidebook. See [www.invo.org.uk/wp-content/uploads/2011/12/INVOLVENRESfinalStatement310309.pdf](http://www.invo.org.uk/wp-content/uploads/2011/12/INVOLVENRESfinalStatement310309.pdf)
- Global database Uber Research <http://www.uberresearch.com/>. The [Sight Loss and Vision PSP](#) has a positive experience of using this tool and it could be useful for other PSPs.

### What could we change in the longer term?

- JLA could have more communications and examples of where priorities have been funded - not just in the newsletter but in other communications e.g. Twitter feed.
- JLA to make more links in their communications to the Research Waste Agenda as an important principle of the JLA (and NETSCC). Relevant paper here: [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)62229-1/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)62229-1/abstract)

### What needs more formal evaluation?

- Which questions (Top 10, workshop shortlist, interim voting list, original long list) have the most impact on research funding and culture?
- How do we best engage the research funding community in the outputs of JLA PSPs, especially as PSPs are now producing research priorities that address social research, basic research etc?
- Is there evidence that sometimes researchers take PSP priorities and manipulate them for the purposes of grant applications?
- Is the credibility of the JLA a barrier or an enabler to research communities taking account of JLA PSP Top 10s?

## 5.2 Involving patients the public (and other stakeholders) in JLA processes more effectively

### What could we change in the short term?

- JLA emphasising that the final workshop be as representative of the range of perspectives as it can be from both patient, public and clinical communities.
- Consider having the final workshop questions 'badged' with the % of ownership by any particular group, especially patients?

### What needs more formal evaluation?

- Have we really understood the level and nature of patient and public involvement in JLA PSPs? Is there a danger that it will become a 'tick box' exercise for PPI? *Do we understand the barriers (cost, literacy, time, etc)? We could evaluate the impact that patients have on the discussions about scoping, or how questions are formulated or different priorities in different groups.*
- What is the best way to get the best questions from patients and carers? *Best in terms of research question that honours the original intention of the suggestion. Also do patients have difficulties thinking beyond their own experience, is this a problem?*

- How do PSPs ensure that the different stages of a disease or health process are represented - perspectives may differ considerably?
- What motivates and encourages clinicians to get involved in research priority setting and JLA PSPs in particular?

### 5.3 Impact of JLA on funded research and research culture

#### What can we do in the short term?

- Encourage reflection and improvement during the lifetime of a PSP.

#### What can we change in the longer term?

- PSPs could do more to maximise the output of the experience (not just priorities) e.g. papers about the engagement and involvement experience from the different partners' perspectives.
- We still need to educate research funders about the JLA and its products. We assume that they know what they have in their hands with a JLA branded research priority.

#### What needs more formal evaluation?

- We need to keep evaluating what has happened with the Top 10s. Should there even be any more PSPs when the priorities from the existing ones haven't all been funded?
- The softer cultural impacts of PSPs are potentially more difficult to measure, but are potentially just as important. *For example what is the value of such widespread engagement in PSPs? Does clinical involvement in PSPs change mindsets of clinical practice? Do patients develop a greater understanding and become more active in the landscape of health research as a result of PSP involvement?*

### 5.4 JLA going global and being adapted

#### What can we do in the short term?

- Communicating that there are official PSPs and non-official ones. *If the latter are not so well done and don't adhere to the JLA values then this may harm the integrity of the JLA. The JLA needs to blossom, but maintain the quality and integrity of the process.*
- Ensuring that the message that PSP priorities are not patient priorities is clear. They are shared priorities.
- There is a strategic question about who 'owns' the JLA - some feel it is the NIHR, others feel very differently.

#### What could we change in the longer term?

- Develop a strategy for the JLA that addresses its ambition generally, the international profile and take up, and more specifically PSP development issues.
- Can the JLA learn from the evolution of Cochrane?
- JLA could try to capture where there has been useful intentional duplication, if one topic was addressed by two different PSPs in different countries - this could capture the differences in places with, for example, indigenous communities. (NB there has been comparisons of Allison Tong's JLA Chronic Kidney Disease in a day with a more traditional PSP in Canada on Dialysis - there were overlaps.)

## **What needs more formal evaluation?**

- JLA PSPs could be done in settings (regional linking up e.g. communities, Academic Health Science Networks and Collaborations for Leadership in Applied Health Research and Care) or address cross-cutting issues such as public health, or health inequalities. Pilot PSPs in these areas could be trialled and evaluated. It is probably more important that the JLA is seen to be leading edge in this regard than worry about reputational damage in trying out new approaches.
- Is a PSP an intervention or a research process? Either way it needs to have appropriate evaluation to ensure that we understand it's impact. However some think that the JLA PSP approach is complex and should be considered more of an informed conversation between partners that have an interest in shaping the research agenda, this suggests a different sort of assessment.

## 6.0 Reflections from the report author

This felt like an important milestone for the JLA. As someone who was involved in the beginning and helped set out the PSP concept and process, it was always in the knowledge that there was little 'evidence' and even less consensus about the best way to go about a research priority setting partnership. What most people won't know is that in the first PSP in [Asthma](#) we nearly all gave up and went home as it felt so difficult! However, we persevered and what helped us to do this was knowing that if it was difficult for us, then it was likely to be difficult for the people with asthma and respiratory physicians, nurses and physiotherapists who were our partners and to whom we had promised a 'result'.

10 years on and many PSPs later it seems very important to have a critical and honest debate about what has been created both in terms of a research process, but also the JLA's impact on research. The former was always going to be easier than the latter....

I really enjoyed the symposium. From a facilitating perspective participants were open minded, honest and respectful of each other. From a personal perspective it was wonderful to see so many participants who have been involved in the JLA either from the beginning or as it has developed, and have an interest in how it evolves and flourishes.

The amount of material produced from the day was much more than I anticipated - a testament to the focus and application of people participating.

So, what are the key questions facing the JLA? I wrote this in December 2009 as a personal note and following the symposium it still feels relevant for the JLA circa 2015:

- **People** – who participates in the priority setting? Achieving the balance in participation from all relevant perspectives. Ensuring that all these perspectives aren't lost as the priority setting process progresses.
- **Process** – needs to be evidence-based, transparent, robust and inclusive. Demonstrate consistency in decision making within JLA partnerships and shared experiences of priority setting across and between partnerships.
- **Product of research priority setting** – what is reasonable to aim for in terms of numbers and scope of priorities? Thinking through how the priorities will affect the current research agenda in that area (do they present an alternate view?) and subsequent research commissioning. Capturing the impact of priorities on commissioning research practice.
- **Partnership** – investing time and resources as the partnership is the vehicle that delivers the product and ensures that the wider community of interest participates.
- **Politics** – evidence-based, transparent and inclusive priority setting is not widely practised in the UK. This approach challenges the current models and culture of research commissioning and funding. However, politically, it could be argued that priority setting is of the moment! In recession hard decisions need to be made. Priority setting offers a rationale for not investing in some areas of research, as well as commissioning more relevant research.
- **Publicity** – Keeping up the 'drip drip' of learning about priority setting to research commissioners and funders, to establish its credibility, awareness and ambition.

## 7. Appendices

### 7.1 Post it notes

Some of the Post its were used in the small group discussions and there was considerable overlap but for transparency of reporting, here are those that weren't taken to the small groups, in themes:

#### Practical issues

- Need realistic set up costs and resources of different approaches so that sensible decisions can be made.
- Need a separate resource to deal with out of scope uncertainties.
- What is a reasonable cost of a PSP and unreasonable?
- Some PSPs will struggle to get funding - as they aren't fashionable or aren't championed by charities e.g. obesity.

#### Methods development

- Refining doesn't mean simplifying!
- A process whereby clinical leads of PSPs share their experiences with peers would be very useful - online action learning set?
- Really helpful to chart the evolution of the JLA for both researchers/health professionals and patients perspectives.
- Is JLA social research about what health research uncertainties matter to patients, carers and clinicians?
- Should and how can the JLA method be extended beyond treatment uncertainties?
- JLA needs a definition of an uncertainty that is non-randomised study/non-interventional, or to revisit the definition of uncertainty to be more broad, and what is the role of very large multicentre trials in the absence of a systematic review that addresses the uncertainty?
- Does evidence checking matter in the PSP process?
- What is the place of research recommendations as sources of research uncertainty? Some PSPs use them and some don't.
- Formalising a process helps create equality as everyone knows the rules and roles, but if the formal process is more familiar to some then it can make participation less.
- More focus on defining outcomes in research questions that are developed from uncertainties as this will help research 'ability'.
- More clarity in Guidebook about interventions that are in JLA scope (lots of Post it notes along these lines).
- More clarity in Guidebook about including uncertainties from Cochrane reviews etc.
- More guidance in Guidebook and discussion about deciding scope and implications of scope choices.

#### Steering Group and PSP engagement

- Useful to have a pre-meet of only patients/public to have a separate conversation?
- Not engaging with researchers may be a barrier to implementation and take up of priorities.
- What about involving policy makers, managers and tax payers (especially for public health)?
- GP involvement remains possibly the most elusive and important stakeholder?
- Are we taking advantage of the partnership in PSP?
- Need to make sure that Steering Group Chairs (Advisers) deal with clinicians who are certain of uncertainties!

## **Gathering uncertainties**

- No harm in having international responses to JLA surveys.
- Need a broad understanding of intervention such as information provision/advice and social interventions, clinicians as interventions, public health interventions.
- Mustn't make assumptions about what we think or know 'works'. Need to refer to evidence.
- Resist the inclusion of too many stakeholders in defining uncertainties so as not to 'water down' experiences of health professionals and patients.
- Values and equality issue - need extra resources and effort to include hard to reach groups such as disabled and young people.
- Need guidance on how to deal with large response and limited resources.
- Questions about cause are not so well served by Systematic Reviews, neither are questions about systems - this is a real challenge for broadening priority setting.

## **International reach of JLA**

- JLA needs to find a way of keeping tabs on what is going on in its name or allied to the JLA; does it matter if we don't know?
- Going international - Apple, Cochrane or UN!!

## **Prioritisation**

- Merit in finding the priorities of different groups but with limited allocated resources shared priorities make more sense.
- Do research priorities actually reflect Quality of Life priorities?
- Is there tension between uncertainties and researchable questions?

## **Funding priorities**

- Is there merit in getting JLA processes embedded in their processes?
- What is the best way to gather info on funded priorities?
- Should we consider changing the language from uncertainty to research recommendation?
- Need to find a way for PSPs to engage more fully with research funders and funding communities.
- Map of funders.

## **Dissemination**

- Need transparent reporting but who will publish methodological papers?

## 7.2 Symposium Programme

James Lind Alliance (JLA) Symposium 23 June 2015, Westminster Central Hall, London

### Learning from JLA Evaluations - Shaping Future JLA Methods

#### Participants will:

- Share experiences of JLA evaluation activity in PSP methods, and outcomes
- Consider the evaluations presented, in light of JLA methods development
- Establish the main issues identified at the symposium for future research and evaluation of JLA prioritisation and engagement

10.00	Registration, refreshments and networking	
10.30	Welcome	Steph Garfield-Birkbeck
10.35	Overview of Symposium	Sally Crowe
10.40	James Lind Alliance: where have we come from and where are we now?	Katherine Cowan
11.00	Introduction to JLA evaluation - what we are aware of and what might be 'out there'. 'Snap shots' of JLA evaluation activity;	Sally Crowe
	<ul style="list-style-type: none"><li>• Do we diminish patient and carer contributions to JLA PSPs by the way we interpret the data?</li></ul>	Rosamund Snow/Joanna Crocker
	<ul style="list-style-type: none"><li>• How does the way we communicate and interact within PSPs affect the outcomes?</li></ul>	Seilin Uhm
	<ul style="list-style-type: none"><li>• What is the best way to collect treatment uncertainties from patients/carers, from a coverage and economical point of view?</li></ul>	Sandra Regan/Sophie Petit-Zeman
	<ul style="list-style-type: none"><li>• Can you "do" JLA in a day?</li></ul>	Allison Tong
11.50	Clarifications	
12.00	Comfort break	
12.15	Respondents - followed by group discussion	Simon Denegri Mary Madden
12.45	Setting research priorities: who's involved, how and does it make a difference?	Sandy Oliver
13.15	Lunch	

14.00

### **Small Group Discussions**

*Aim: to take account of the evaluations described and address these, and issues identified by the participants (on Post it notes during the morning)*

#### **Group 1: JLA process**

- Initiation, scoping and engagement
- Data gathering, management and analysis

Facilitator: David Crowe  
Note taker: Ruairidh Milne

#### **Group 2: JLA process**

- Prioritisation - interim and final
- Publicity, and dissemination

Facilitator: Sheela Upadhyaya  
Note taker: Beccy Maeso

#### **Group 3: Wider research and evaluation issues for JLA to consider; such as impact of priorities, public involvement and engagement**

Facilitator: Richard Morley  
Note taker: Caroline Whiting

#### **Group 4: Developments and adaptations of JLA in other settings, and across the world.**

Facilitator: Katherine Cowan  
Note taker: Steph Garfield–Birkbeck

15.00

Refreshments

15.15

Feedback from small group discussions

Sally Crowe

15.55

Reflections on the day, summing up, next steps

Ruairidh Milne

16.00

Close

### **7.3 Symposium Participants**

Michele Acton	Nick Hicks	Sandra Regan
Martin Burton	Tom Hughes	Amanda Roberts
Mary Busk	Cynthia Joyce	Rosamund Snow
Katherine Cowan	Keith Lloyd	Jean Straus
Joanna Crocker	Louise Locock	Amy Street
David Crowe	Mary Madden	Maryrose Tarpey
Katherine Deane	Beccy Maeso	Carrie Thomson
Simon Denegri	Kath Maguire	Allison Tong
Lisa Douet	Ruairidh Milne	Jennifer Tuft
Mark Fenton	Richard Morley	Seilin Uhm
Steph Garfield-Birkbeck	Chris Morris	Sheela Upadhyaya
Andy Gibson	Sandy Oliver	Matt Westmore
Helen Henshaw	Sophie Petit-Zeman	Caroline Whiting
		Philippa Yeeles

## **7.4 Abstracts**

### **Is the JLA PSP process biased against patients and carers?**

Rosamund Snow and Joanna Crocker

#### **What we did**

This study explored what might stop patients and carers from making a difference during the first stage of a James Lind Alliance Priority Setting Partnership (JLA PSP). Patients, carers and healthcare professionals were invited to submit suggested research questions about treatments for Type I diabetes via an online and paper survey in 2010. However, the Partnership had to follow rules about what counted as a valid question. This meant that 22% of suggested questions were rejected at this first stage. We did a statistical analysis to find out who was most likely to have their suggestions rejected at this stage: patients, carers, healthcare professionals and others. We also looked at the rejected questions in detail to see what they were about.

#### **What we found**

- Patients and carers were more likely to have a suggestion rejected than healthcare professionals and others who had never lived with diabetes.
- The rejected questions were mostly about cure, cause, prevention, and understanding diabetes in more depth.
- There were also treatment-related questions about healthcare policy and practice, including access to treatment, quality of care and the “treatment” of people with diabetes by others in society.

#### **Implications for the JLA**

Our findings suggest that:

- To help patients and carers make more of a difference, JLA PSPs should ideally involve patients and carers from the very beginning, helping to decide what kind of questions should be considered.
- JLA PSPs should plan how to deal with suggested questions which fall outside the agreed scope of the PSP but could still be researched.
- JLA PSPs should clearly report how and why suggested questions are rejected. Could patients and carers be involved in decisions about rejection? Could there be any feedback to individuals about why their suggestions were rejected?

## **Preterm Birth Priority Setting Partnership**

Seilin Uhm

The [Preterm Birth PSP](#) adapted the five stages of JLA's approach to identify and prioritise research uncertainties about babies born too soon, their mothers and families.

We had 13 steering group meetings and conducted two big surveys: one to ask 'what we do not know about preterm birth' and another one to select 'which questions are more important'.

From the outcomes of national surveys, we firstly found out that there were different interests and priorities between service users, clinicians, and researchers. When participants voted, we asked whether they were service users, clinicians or people who were both service users and clinicians. Clinicians' priorities tended to differ from the priorities of the other two groups.

Secondly, we realised that there were language and cultural gaps between these groups which would cause communication issues. Agreeing on a taxonomy to support clear communication was more challenging than expected.

Thirdly, during the final workshop, we discovered that while there were some research questions which were included as top priorities consistently (for example, general prevention of preterm birth), there were other questions which were not finally included even though they were in the top of the list from the voting outcomes (for example, stress and physical workload in pregnancy, or preventing subsequent preterm births).

Including different groups for this process was necessary because the existing research agenda from systematic reviews or clinical guidance was not enough to cover interests from service users and clinicians, who had to deal with difficulties with preterm birth every day. Effective communication tools (such as an agreed taxonomy or comprehensive glossary) were also important.

## **Gathering treatment uncertainties from patients/carers using different methods: Evaluation Report for NIHR Oxford Biomedical Research Centre (BRC)**

Prepared by Sally Crowe and Sandra Regan; Crowe Associates Ltd for the NIHR Oxford Biomedical Research Centre in association with the Oxford Health Experiences Research Group, and the JLA [Hip and Knee Replacement for Osteoarthritis Priority Setting Partnership](#); with input from Tessa Clark and Alix Brazier. July 2014.

This project compared three different ways by which the JLA can gather research questions from patients and carers: survey; discussion groups; and extracting information from interviews gathered by [Healthtalkonline](#) (HTO).

This was the first time that all three methods had been used in a PSP – the PSP on hip and knee replacement for osteoarthritis. The study aimed to assess which method had the most impact by looking at their contributions to the top 10 priorities, and which was the most cost-effective.

We found that in the final prioritised list, nine of the top ten were contributed to by the patient/carer survey, of which five also came from patient/carer discussion groups, and one from HTO interviews. Of the five that came from the discussion groups, two also came from HTO interviews. One question came from the HTO interviews alone.

In this instance, the HTO interviews did not incur costs, but this is not usually the case. To assess cost-effectiveness of the other two methods we looked at three different ways of attributing direct costs. Thus, for the survey and discussion groups, in two of the three comparisons, the survey emerged as most cost-effective in the case of this PSP.

## Research priority-setting in chronic kidney disease: a one-day workshop

Allison Tong, Sally Crowe, Shingisai Chando, Alan Cass, Steve J Chadban, Jeremy R Chapman, Martin Gallagher, Carmel M Hawley, Sophie Hill, Kirsten Howard, David W Johnson, Peter G Kerr, Anne McKenzie, David Parker, Vlado Perkovic, Kevan R Polkinghorne, Carol Pollock, Giovanni FM Strippoli, Peter Tugwell, Rowan G Walker, Angela C Webster, Germaine Wong, Jonathan C Craig.

### Summary

A national one-day workshop was convened in Australia to generate and prioritise research questions in chronic kidney disease among diverse stakeholder groups. Patients with chronic kidney disease (n=23), nephrologists/surgeons (n=16), nurses (n=8), caregivers (n=7), and allied health professionals and researchers (n=4) participated.

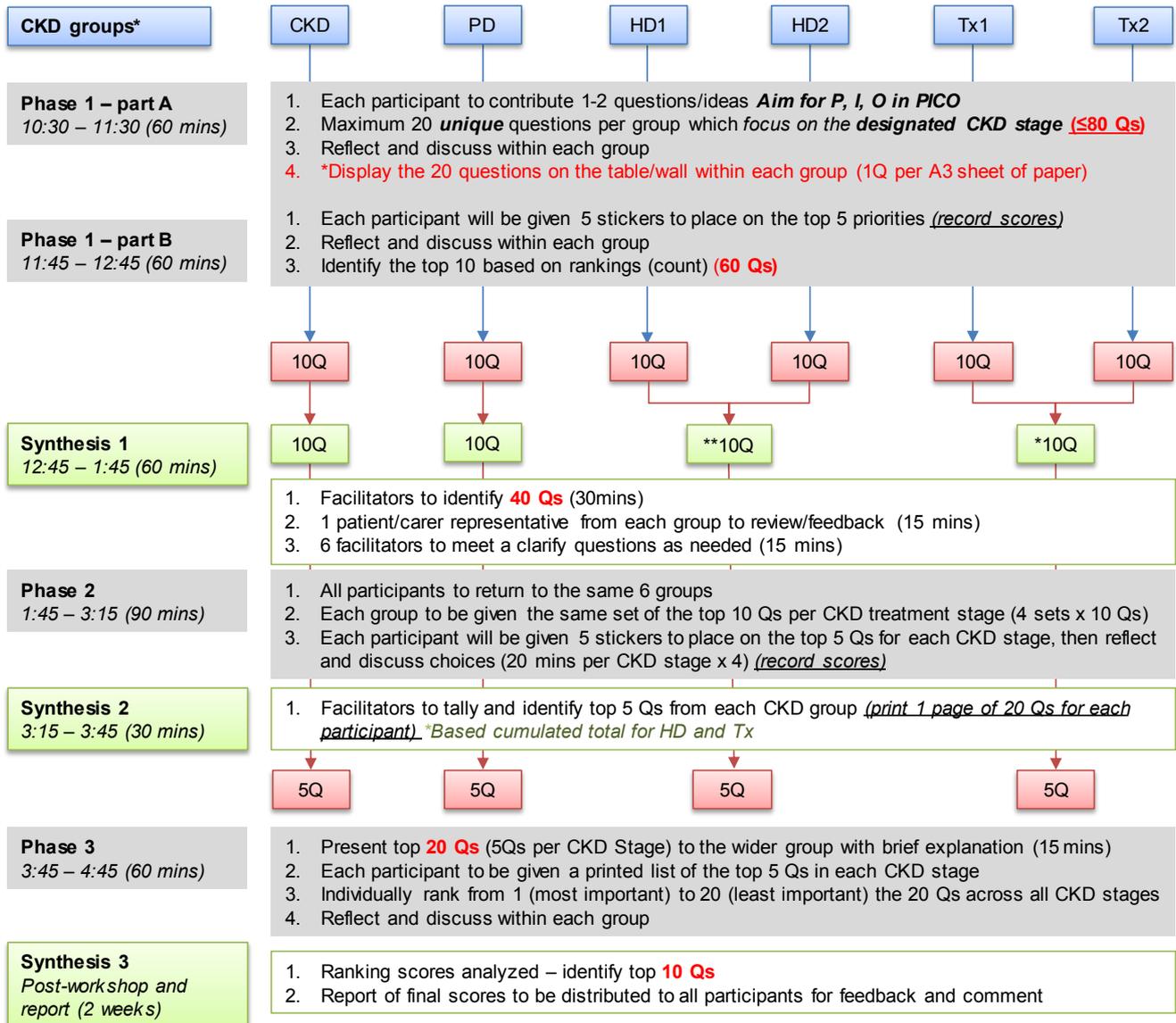
Participants were divided into groups of 8 to 10, and generated intervention questions across four treatment categories: non-dialysis dependent chronic kidney disease, peritoneal dialysis, haemodialysis, and kidney transplantation.

Each participant was given 5 votes to prioritise the questions. The top 10 questions with the most votes were taken to the next round. Each group discussed and ranked priorities for all four treatment categories. The top 5 ranked from each stage were taken through to the next round. The votes were summed and the top 5 questions from each stage of chronic kidney disease were generated into a list of 20 questions. Each participant individually ranked the top 20 questions from 1 (most important) to 20 (least important). The process is depicted in **Figure 1**.

The 5 highest ranking questions (in descending order) were as follows:

- How effective are lifestyle programs for preventing deteriorating kidney function in early chronic kidney disease?
- What strategies will improve family consent for deceased donor kidney donation, taking different cultural groups into account?
- What interventions can improve long-term post-transplant outcomes?
- What are effective interventions for post haemodialysis fatigue?
- How can we improve and individualise drug therapy to control post-transplant side effects?

Priority questions were focussed on prevention, lifestyle, quality of life, and long-term impact. These prioritised research questions will be used to inform funding agencies, patient/consumer organisations, policy makers, and researchers in developing a chronic kidney disease research agenda that is relevant to key stakeholders.



**Figure 1. Process** CKD, chronic kidney disease; PD, peritoneal dialysis; HD, haemodialysis; Tx, transplantation, Q, question

## Research Priority Setting in Kidney Disease: A Systematic Review

Allison Tong, PhD, Shingisai Chando, MPH, Sally Crowe, PG Dip, Braden Manns, MD, MSc, Wolfgang C. Winkelmayer, MD, ScD, Brenda Hemmelgarn, MD, PhD, and Jonathan C. Craig, PhD

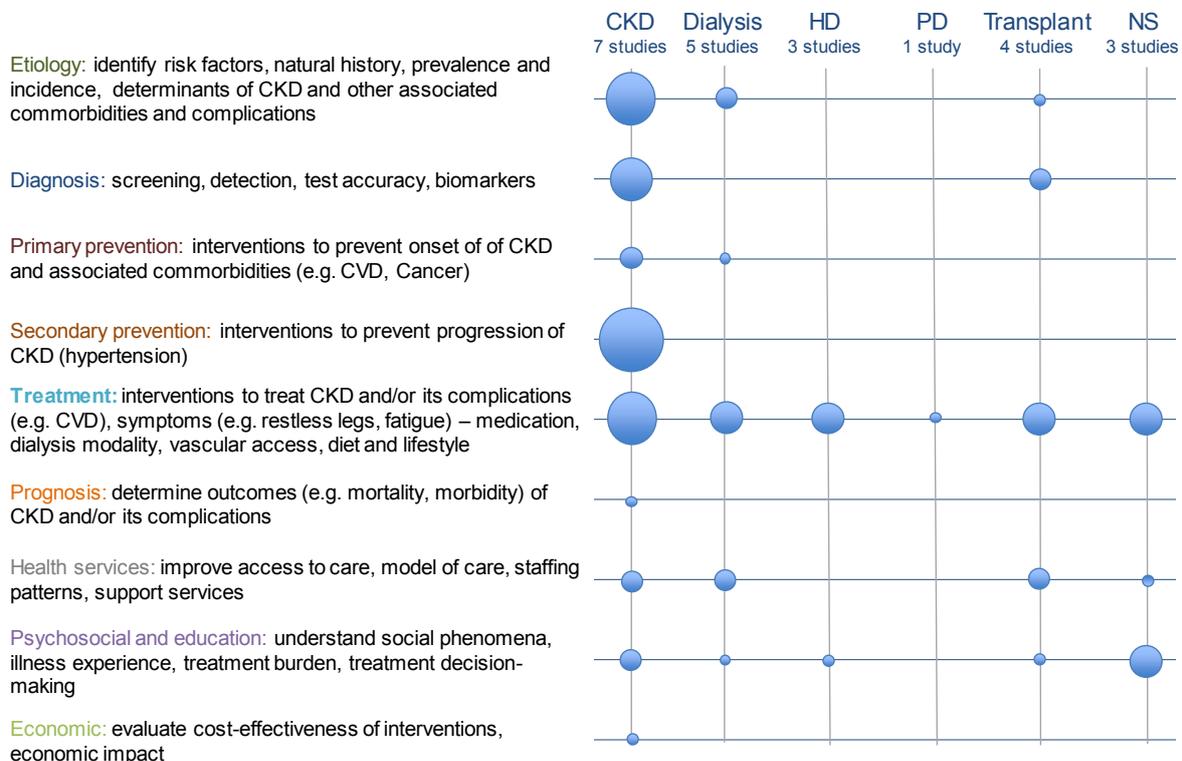
### Plain Language Summary

Resources for research are insufficient to cover all unanswered questions, and therefore difficult choices about allocation must be made. Recently there has been a move toward more patient-centred research. This review of research evaluated original approaches to research prioritisation in kidney disease. The review also describes the research priorities of patients with kidney disease, their carers, the health care providers involved in their care, and policy makers.

16 studies were identified which were conducted in the United States, the Netherlands, Australia, Canada, and internationally. Only 4 of the studies explicitly involved patients. Various priority-setting methods were used, including the Delphi technique, expert panels, consensus conference, ranking or voting surveys, focus groups, and interviews. 11 of the included studies in the review described these processes in detail.

The priority areas for research most frequently identified across studies were prevention of acute kidney injury, prevention of chronic kidney disease progression, fluid and diet restrictions, improving vascular access, kidney transplant survival, access to transplantation, patient education, and psychosocial impact of chronic kidney disease. However, without the explicit involvement of patients and carers it is difficult to know if these are priorities shared by people with kidney disease and their carers.

The authors suggest that establishing research priorities using a pre-specified and transparent process that engages patients, carers, and health care providers is needed to ensure that resources are invested to answer questions that address the shared priorities in kidney disease.



CKD = Chronic Kidney Disease, HD = Haemodialysis, PD = Peritoneal Dialysis NS = Not Specific. Size of the circles indicates the number (n) of studies identifying the question type as a research priority.

## **Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch.**

Sally Crowe, Mark Fenton, Matthew Hall, Katherine Cowan, Iain Chalmers

Accepted for Research Involvement and Engagement May 2015

### **Plain Language Summary**

There is some evidence that there is a mismatch between what patients and health professionals want to see researched, and the research that is actually done.

The James Lind Alliance (JLA) research Priority Setting Partnerships (PSP) were created to address this mismatch. Between 2007 and 2014, JLA partnerships of patients, carers and health professionals agreed important treatment research questions (priorities) in a range of health conditions, such as [type 1 diabetes](#), [eczema](#) and [stroke](#).

We were interested in how much these JLA PSP priorities were similar to treatments undergoing evaluation and research, over the same time span. We identified the treatments described in all the JLA PSP research priority lists and compared these to the treatments described in a group of research studies (randomly selected) registered publicly.

The priorities identified by JLA PSPs emphasised the importance of non-drug treatment research, compared to the research actually being done over the same time period, which mostly involved evaluations of drugs. These findings suggest that the research community should make greater efforts to address issues of importance to users of research, such as patients and health care professionals.

## 7.5 Table of known JLA evaluation projects

Title	Commentary	Link to publication, report and more information
<p><b>Missed opportunities for impact in patient and carer involvement: a mixed methods case study of research priority setting</b></p>	<p>Re analysing data from the Type 1 Diabetes PSP to find out which groups of respondents were most likely to have their suggestions rejected and what these suggestions were about.</p>	<p><a href="http://www.researchinvolvement.com/content/1/1/7">http://www.researchinvolvement.com/content/1/1/7</a></p>
<p><b>Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch</b></p>	<p>Treatment research priorities generated by the first 14 JLA PSPs were reviewed to assess whether, on average, treatments prioritised by patients and clinicians differ importantly from those being studied by researchers.</p>	<p><a href="http://www.researchinvolvement.com/content/1/1/2">http://www.researchinvolvement.com/content/1/1/2</a></p>
<p><b>How does the way we communicate and interact within PSPs affect the outcomes?</b></p>	<p>As part of a PhD and embedded in the JLA Pre Term Birth Research Priority Setting Partnership, the author explores the different communication styles within the research partnership and how decisions were made.</p>	<p>Key contact Seilin Uhm <a href="mailto:s.uhm@ioe.ac.uk">s.uhm@ioe.ac.uk</a></p>
<p><b>What is the best way to collect treatment uncertainties from patients/carers, from a coverage and economical point of view?</b></p>	<p>This study compared three different ways by which the JLA can gather research questions from patients and carers : surveys (the traditional JLA approach), discussion groups and extracting data from interviews on the patient experience website <a href="#">Healthtalkonline</a>. This was the first time that a PSP had used all three methods and the study aimed to assess which was the most impactful and cost-effective.</p>	<p>Report available here: <a href="http://oxfordbrc.nihr.ac.uk/wp-content/uploads/2013/11/Final-Evaluation-Report.pdf">http://oxfordbrc.nihr.ac.uk/wp-content/uploads/2013/11/Final-Evaluation-Report.pdf</a></p>

<p><b>Testing the Public Involvement Impact Assessment Framework with a JLA PSP</b></p>	<p>This project trialed PiiAF as an assessment tool for use in a JLA PSP (Kidney Transplant).</p>	<p>More information about PiiAF: <a href="http://piiaf.org.uk/">http://piiaf.org.uk/</a></p> <p>Report available here: <a href="http://oxfordbrc.nhr.ac.uk/wp-content/uploads/2013/11/Measuring-PPI-impact.pdf">http://oxfordbrc.nhr.ac.uk/wp-content/uploads/2013/11/Measuring-PPI-impact.pdf</a></p>
<p><b>Can you "do" JLA in a day?</b></p>	<p>This project aimed to explore if treatment research priorities in chronic kidney disease could be achieved via a one day workshop incorporating elements of the JLA approach.</p>	<p>Report for the public here: <a href="http://kidneyandtransplant.cochrane.org/sites/kidneyandtransplant.cochrane.org/files/uploads/CKDpriorities-workshop_summaryreport_FINAL_140414lowres.pdf">http://kidneyandtransplant.cochrane.org/sites/kidneyandtransplant.cochrane.org/files/uploads/CKDpriorities-workshop_summaryreport_FINAL_140414lowres.pdf</a></p>
<p><b>How do research priorities from a JLA PSP compare to what is current and ongoing research?</b></p>	<p>A Review that explores the extent to which recently completed and ongoing clinical research was consistent with priorities identified by patients, caregivers, and clinicians, via a JLA PSP in Dialysis.</p>	<p>Published paper here (paywall): <a href="http://www.ncbi.nlm.nih.gov/pubmed/25943716">http://www.ncbi.nlm.nih.gov/pubmed/25943716</a></p> <p>(IN PRESS) Assessing the extent to which current clinical research is consistent with patient priorities: a scoping review using a case study in patients on or nearing dialysis</p> <p>Min Jun MScMed (ClinEpi) PhD, Braden Manns MD MSc<sup>2</sup>, Andreas Laupacis BA MD MSc, Liam Manns, Bhavdeep Rehal BSc, Sally Crowe, Brenda R Hemmelgarn MD PhD</p>
<p><b>Case study: a patient-clinician collaboration that identified and prioritized evidence gaps and stimulated research development.</b></p>	<p>The authors follow up and discuss the outcome of a JLA PSP in Urinary Incontinence after a year had elapsed.</p>	<p><a href="http://www.ncbi.nlm.nih.gov/pubmed/21816575">http://www.ncbi.nlm.nih.gov/pubmed/21816575</a></p>