PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (http://bmjopen.bmj.com/site/about/resources/checklist.pdf) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

| TITLE (PROVISIONAL) | The James Lind Alliance Process approach: A scoping review | |
|---------------------|--|--|
| AUTHORS | Nygaard, Agnete; Halvorsrud, Liv; Linnerud, Siv; Grov, Ellen Karine; Bergland, Astrid | |

VERSION 1 - REVIEW

| REVIEWER | Kristina Staley TwoCan Associates, UK. I have worked for ten different James Lind Alliance Priority Setting Partnerships as an Information Specialist, processing the responses to initial surveys. | |
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| | I am a co-author on a journal article under review from one of the PSPs I worked on. | |
| | I (and my collaborator Sally Crowe) have been funded by Oxford University and NETSCC to undertake an evaluation of JLA PSP top tens to review how much influence they have on the wider research agenda. | |
| REVIEW RETURNED | 26-Nov-2018 | |

| GENERAL COMMENTS | This is the first scoping review of published studies that have used the JLA approach. The authors have conducted this review to high standard and their conclusions and observations are sound. However, my concern is that this review is not providing new insights and therefore is not of the calibre for a BMJ article. I would recommend the authors resubmit elsewhere. |
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| | The intention of journal articles that result from JLA PSPs is often to publicise the top ten research priorities to specialist audiences with an interest in the topic of the PSP. They are less concerned with the process that was followed, although the details of the JLA approach are described. Therefore these articles do not always provide sufficient detail of any learning from the experience. By focusing on the details of the process (how many people took part, how many steps were involved, how many questions were put forward etc) they aim to give a sense of the breadth and scope of the work. However, these details do not provide a sense of the impact of the involvement, which more often relates to the development of consensus, the discussions amongst all the people who took part, the distribution of power and the politics. An evaluation of the JLA process as a form of patient and public involvement would need to consider these less tangible aspects of |

the process to genuinely assess how much influence patient/public partners had during the process.

The authors highlight concerns about the JLA process which may limit the access of ethnic populations or groups that are harder to engage. This is well-recognised and is often debated as part of the PSP process. Two of the recent PSPs I have worked on have taken additional steps to address these concerns and have enabled minority groups and people with learning disabilities to complete the surveys other than online. Each PSP may need to adapt its processes to respond to these issues in ways that specifically address the needs of the people they want to engage.

I agree with the authors on their conclusions, but do not believe this is a new insight provided by this scoping review. Lack of diversity amongst the people involved is a common concern about PPI processes more generally, and one which many projects are now taking steps to address.

| REVIEWER | Andreas Laupacis St. Michael's Hospital, Toronto, Canada |
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| REVIEW RETURNED 26-Nov-2018 | |

GENERAL COMMENTS

The authors conduct a scoping review of articles published in the peer-review literature between 2011 and 2018 that have used the James Lind Alliance (JLA) methodology to identify research priorities.

Overall, this is a well written manuscript. I will initially comment on some aspects of the manuscript in the order in which they appear, and then end with two other comments.

Page 2 line 6: 33 studies met the inclusion criteria of this study. When I looked at the JLA website they list 74 Priority Setting Partnerships that have developed a Top Ten list. There's a large difference between 33 and 74. Some of this difference might be explained by the fact it that it takes some time for the PSP's finished in 2017 and 2018 to be published in the peer reviewed literature. However it would be interesting to know why there is such a discrepancy in numbers.

Page 3 line 3: the authors indicate that in general patients of lower socioeconomic status or who are disadvantaged are less likely to participate in JLA processes than other patients. In my own experience, I absolutely agree with this criticism. However, it wasn't clear to me how the authors came to this conclusion. How many of the 33 articles actually described the SES characteristics of those who participated in the JLA process? Patients can participate at different stages; on the steering committee, by suggesting research uncertainties on the website, participating in the interim priority setting process, and participating in the workshop. It would be interesting to know whether the characteristics of the patients participating in the JLA were actually described in most studies, or whether the conclusion that the authors have reached (which I agree with), were based upon a few studies that reported this.

Page 8 line 17: I do not understand this sentence. It says "Patients and the public were not involved in this study." But in order to be a JLA process, patients do have to be involved....??? Page 8 line 27: I don't understand how a project was eligible for this study if the JLA guidelines were not used.

Page 21 line 35: the authors indicate that patients and carers submitted more questions regarding psychosocial issues than clinicians. This appears to have been based upon the findings of 3 studies. What did the other 30 studies find? If only 3 studies reported on this, is it possible that there is reporting bias here, with studies that have found this difference reporting them and those that didn't find a difference not reporting them?

Page 24 line 34: I didn't understand what the "top 25" meant.

Page 26 line 8: the authors of this study indicate that the authors of JLA projects argue that basic research endeavors do not lead to results that are useful to the end user. I didn't see any reference to

results that are useful to the end user. I didn't see any reference to this, and I disagree with this comment. I think it is a mistake to think of the JLA process as prioritizing non basic science research. For example, a PSP I was involved in with dialysis patients and clinicians ended up prioritizing research in the causes and effective treatments of itching. It is impossible to develop an effective treatment for itching without understanding the basic science mechanisms that cause itching.

Page 26 line 16: the authors indicate that their findings were consistent with those of Sally Crowe that found a mismatch between treatments that patients and clinicians wanted to evaluate and ones that are being evaluated by researchers. I agree that is what Ms. Crowe found, but I didn't see anything in the data that these authors collected from the 33 publications that would allow them to reach those conclusions from their scoping review. Page 28 line 24: I agree that the top 10 priorities need to be written in a language that is understandable to everyone. Having said that, in my experience many PSP's come up with different ways of communicating the results of their PSP, and a peer reviewed publication is only one of them. For example, patient advocacy groups often email the top ten to their constituencies, put them in newsletters or send letters to specific end users. In those methods of communication, they often use very different language than what is used in their peer-reviewed publications. The authors of the scoping review have chosen to look at peer reviewed publications, which by definition will use the most academic language.

Let me end with two other comments.

The authors didn't address some of the questions that I am often asked about by people who are considering a JLA process, and that might have been useful to look at in a scoping review such as: how much will it cost, how long will the PSP take, and do I need to submit this project to a Research Ethics Board? Did any of the 33 papers address these issues? Regarding the latter, my understanding is that in the UK a JLA process is not considered research, while in Canada it is. This could markedly lengthen the length of time it takes to do a PSP in Canada.

Finally, I note that the reference for Barnieh (reference 33) is the wrong one. The reference describing the results of that PSP is published with Manns B as the first author in Clin J Am Soc Nephrol in 2014.

| REVIEWER | Kerry Woolfall University of Liverpool |
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| REVIEW RETURNED | 03-Feb-2019 |

| GENERAL COMMENTS | This is a clearly written, well conducted scoping review, which will | | |
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| | be useful for researchers designing JLA processes in the future. | | |

| The paper highlights an important point about representativeness |
|--|
| of JLA process participants- although this is more of a presumption |
| as data to support this claim is not presented the findings. This |
| point could be made in the limitations. The first line of the abstract |
| conclusion would be improved and reflect the study findings more |
| closely if it was replaced with the first line of the main conclusion: |
| JLA-based PSP makes a useful contribution to identifying research |
| questions. |

| REVIEWER | Jennifer Bethell |
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| | Canada |
| | I have been involved with two James Lind Alliance Priority Setting |
| | Partnerships. |
| REVIEW RETURNED | 22-Mar-2019 |

GENERAL COMMENTS

Thank-you for the opportunity to review this scoping review. It is timely and relevant. Since inception, the James Lind Alliance (JLA) has developed an international reputation for involving patients, caregivers (friends and family) and clinicians in setting shared research priorities through Priority Setting Partnerships (PSPs). This scoping review has the potential to make an important contribution.

My main concern is that the paper places too much emphasis on describing the JLA methods; there is a detailed, freely-accessible online JLA PSP guidebook and, as the authors themselves point out (page 5, lines 15-22): "once a partnership is set up, there is a defined process for collecting uncertainties and interim priority setting, which leads to a list of approximately 20-30 uncertainties used in a final priority setting workshop at which a top 10 list of priorities is agreed upon".

I suggest this paper would benefit from describing the characteristics of the PSPs, elaborating on aspects they may have operationalized the JLA methods differently (e.g., in gathering and verifying uncertainties), and then offering some analysis (e.g., making recommendations for reporting and/or identifying gaps for research).

MAJOR ISSUES:

Objective and questions: The objective of the scoping review, as stated in the paper on page 5 (line 35): "...this scoping review describes the JLA approach to the PSP process and how it is used to identify treatment uncertainties and develop top 10 priority lists". With this description, it is unclear how this scoping review differs from the JLA PSP guidebook: http://www.jla.nihr.ac.uk/jla-quidebook/

Some of the questions guiding the review should be refined. For example, page 5 (line 42), lists question 1 as "What characterizes.... adherence to the JLA approach...?"; these are all JLA PSPs, so presumably they all adhere to the JLA approach. This also makes the meaning of "if the JLA guidelines were used" statement (page 8, line 27) unclear. Also, page 5 (line 47), lists question 2 as "How are PSPs organized?"; this is vague and, therefore, it's unclear if it is ever answered. Conversely, page 5 (line 49), question 3 is posed clearly and presents a question that

could provide important context and analysis on the PSP process: "What processes are used to gather and verify uncertainties?". In the discussion, the authors focus much attention on how few studies have explored ways to reach vulnerable groups; this is an important point to cover, so could it have been formulated into a question for the scoping review?

Methods: it is not always clear how many reviewers were involved in each phase of study selection. Also, as a scoping review, it is unclear why other sources were not consulted, and in particular, the JLA coordinating centre or website (see comments under "limitations" below).

Results: The main table is 12 pages long and quite text heavy, so it would be helpful if the information in the first paragraph of the results (page 21, lines 11-45) were summarized in a table. Also, the results are not fully aligned with the research questions. As an example, on page 21, line 35: "...compared with clinicians, patients and carers contributed a greater number of questions regarding psychosocial issues, psychosocial stress, depression and anxiety" - was distribution of questions by respondent type part of the data extraction? (it is not typically reported as the JLA is designed to identify shared research priorities). This is also mentioned in the discussion (page 25, line 50).

Although question 3 states "what processes are used to gather and verify uncertainties", neither is reported in table 2 and I can't see that methods for verifying uncertainties was addressed.

Limitations: Although they identify limitations to the JLA process (in the article summary), the authors do not discuss limitations to their scoping review except to say that: (1) they may not have identified all relevant studies and (2) they did not search the grey literature because they assumed "research using the JLA approach would be found in indexed databases". Limitation (1) could have - and probably should have - been addressed by contacting the James Lind Alliance coordinating centre; they track outcomes of the PSPs and, therefore, likely could have been involved in checking the completeness of the author's reference list - or the authors could have checked the JLA website which lists all PSPs. Limitation (2) is important in this context; PSPs sometimes produce peer reviewed papers and sometimes also/instead produce more detailed reports available through partner organisations (i.e., grey literature). Again, the JLA coordinating centre/website may have assisted with identifying these resources. However, if this was outside the scope of the review, this should be acknowledged as a limitation. Finally, another related limitation is that, for some papers, the JLA methods may not have been described in detail because the authors chose to instead reference the detailed JLA guidebook; in other words, the JLA methods may have been followed closely but not fully reported in the published papers (which are limited in word count). As just one example, page 25 (line 14) notes "Nineteen of the studies used the NGT in the final priority setting workshop" – it is likely more (or all) did, but some did not explicitly state it.

Conclusions: the conclusions could be better aligned with the questions guiding this scoping review.

MINOR ISSUES:

Page 4, line 12: implies PPI is achieved "through discussion" but, in fact, patients and public are sometimes more involved than that (e.g., patients have been involved in data collection, dissemination, etc.)

Page 4, line 19: authors could acknowledge that although PPI has numerous proposed advantages, but evidence is still relatively limited

Page 4, line 22: it may be more accurate to say "... PSP to define and prioritize treatment uncertainties..."

Page 5, line 8: "JLA provides independent facilitation and guidance in the identification and prioritization processes" – the JLA provides facilitation and guidance throughout the PSP

Page 26, line 10: the statement "authors of these studies argue that many basic research endeavours do not lead to results that are useful to the end-user" should be referenced

Page 26, line 15: it's not clear how the results of this scoping review can be interpreted as finding "mismatch between the treatments that patient and clinicians want to have evaluated and the treatments actually being evaluated by the researchers."

Page 28, line 17: is reference 46 about patient engagement/PSPs?

Page 34, line 45: in context of other exclusions being "not PSP" and "not JLA", what does exclusion "not top 10" mean?

VERSION 1 – AUTHOR RESPONSE

| Number | Reviewers comments | Authors comments | Page, line |
|--------|--|---|------------|
| | Reviewer: 1 | | |
| #1 | This is the first scoping review of published studies that have used the JLA approach. The authors have conducted this review to high standard and their conclusions and observations are sound. However, my concern is that this review is not providing new insights and therefore is not of the calibre for a BMJ article. I would recommend the authors resubmit elsewhere. | This is nice to hear that this review is conducted to high standard and the conclusions and observations are sound. | |
| | The intention of journal articles that result from JLA PSPs is often to publicise the top ten research priorities to specialist audiences with an interest in the topic of the PSP. They are less | | |

| | concerned with the process that was followed, although the details of the JLA approach are described. Therefore, these articles do not always provide sufficient detail of any learning from the experience. By focusing on the details of the process (how many people took part, how many steps were involved, how many questions were put forward etc) they aim to give a sense of the breadth and scope of the work. | | |
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| #2 | However, these details do not provide a sense of the impact of the involvement, which more often relates to the development of consensus, the discussions amongst all the people who took part, the distribution of power and the politics. An evaluation of the JLA process as a form of patient and public involvement would need to consider these less tangible aspects of the process to genuinely assess how much influence patient/public partners had during the process. | Thank for this important feedback. We have added this information to section limitation of the study | See page 32 lines 22-25 + page 33 lines 1-2 |
| #3 | The authors highlight concerns about the JLA process which may limit the access of ethnic populations or groups that are harder to engage. This is well-recognised and is often debated as part of the PSP process. Two of the recent PSPs I have worked on have taken additional steps to address these concerns and have enabled minority groups and people with learning disabilities to complete the surveys other than online. Each PSP may need to adapt its processes to respond to these issues in ways that specifically address the needs of the people they want to engage. | Thank you for the comment. We have added the following line in the discussion. | See page 30 lines 17-18 |
| | I agree with the authors on their conclusions, but do not believe this is a new insight provided by this scoping review. Lack of diversity amongst the people involved is a common concern about PPI processes more generally, and one which many projects are now taking steps to address. | Thank you so much for agreeing with our conclusion. Furthermore, our intention is to summarize information based individual study and hopefully this will provide new knowledge. | |

| # | Reviewer: 2 | Authors comments | Page, line |
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| #1 | The authors conduct a scoping review of articles published in the peer-review literature between 2011 and 2018 that have used the James Lind Alliance (JLA) methodology to identify research priorities. Overall, this is a well written manuscript. | Thank you. Nice to hear. | |
| #2 | Page 2 line 6: 33 studies met the inclusion criteria of this study. When I looked at the JLA website they list 74 Priority Setting Partnerships that have developed a Top Ten list. There's a large difference between 33 and 74. Some of this difference might be explained by the fact it that it takes some time for the PSP's finished in 2017 and 2018 to be published in the peer reviewed literature. However it would be interesting to know why there is such a discrepancy in numbers. | Thank you for this comment. This is amended. We have added four more studies that met the inclusion criteria. | See page 2 line 16 See the attached table "Table with articles and publications from JLA website". |
| #3 | Page 3 line 3: the authors indicate that in general patients of lower socioeconomic status or who are disadvantaged are less likely to participate in JLA processes than other patients. In my own experience, I absolutely agree with this criticism. However, it wasn't clear to me how the authors came to this conclusion. How many of the 33 articles actually described the SES characteristics of those who participated in the JLA process? Patients can participate at different stages; on the steering committee, by suggesting research uncertainties on the website, participating in the interim priority setting process, and participating in the workshop. It would be interesting to know whether the characteristics of the patients participating in the JLA were actually described in most studies, or whether the conclusion that the authors have reached (which I agree with), were based upon a few studies that reported this | Thank you for the comment. This is amended in the result part. | See page 23 lines 15-19. |

| #4 | Page 8 line 17: I do not understand this sentence. It says "Patients and the public were not involved in this study." But in order to be a JLA process, patients do have to be involved??? | Thank you for noticing this. The statement was deleted by the authors, but see attachments "BMJ Open - bmjopen-2018-027473.R1 requires your attention", bullet point two. Thank you for the | See page 9 lines 9- 10 See page 9 line 14 |
|----|--|--|---|
| #5 | a project was eligible for this study if the JLA guidelines were not used. | comment. This is amended. | See page 9 line 14 |
| #6 | Page 21 line 35: the authors indicate that patients and carers submitted more questions regarding psychosocial issues than clinicians. This appears to have been based upon the findings of 3 studies. What did the other 30 studies find? If only 3 studies reported on this, is it possible that there is reporting bias here, with studies that have found this difference reporting them and those that didn't find a difference not reporting them? | Thank you. Your feedback is useful. This is amended. | See page 23 lines 20-24 |
| #7 | Page 24 line 34: I didn't understand what the "top 25" meant | Thank you for noticing. This is amended. | See page 27 line 6 |
| #8 | Page 26 line 8: the authors of this study indicate that the authors of JLA projects argue that basic research endeavors do not lead to results that are useful to the end user. I didn't see any reference to this, and I disagree with this comment. I think it is a mistake to think of the JLA process as prioritizing non basic science research. For example, a PSP I was involved in with dialysis patients and clinicians ended up prioritizing research in the causes and effective treatments of itching. It is impossible to develop an effective treatment for itching without understanding the basic science mechanisms that cause itching. | Thank you. We agree with this comment. We have deleted it. | See page 28 lines 21-24 |
| #9 | Page 26 line 16: the authors indicate that their findings were consistent with those of Sally Crowe that found a mismatch between treatments that patients and clinicians wanted to evaluate and ones that are | Thank you for noticing. We are totally agreed. We have deleted the sentences. | See pages 28 line 24-24 + pages 29 line 1-2 |

| #10 | being evaluated by researchers. I agree that is what Ms. Crowe found, but I didn't see anything in the data that these authors collected from the 33 publications that would allow them to reach those conclusions from their scoping review. Page 28 line 24: I agree that the top 10 priorities need to be written in a language that is understandable to everyone. Having said that, in my experience many PSP's come up with different ways of communicating the results of their PSP, and a peer reviewed publication is only one of | Thank you for this comment. We added some statement about language and communication in limitation. | See page 33 lines 2-4 |
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| | them. For example, patient advocacy groups often email the top ten to their constituencies, put them in newsletters or send letters to specific end users. In those methods of communication, they often use very different language than what is used in their peer-reviewed publications. The authors of the scoping review have chosen to look at peer reviewed publications, which by definition will use the most academic language. | | |
| #11 | Let me end with two other comments. The authors didn't address some of the questions that I am often asked about by people who are considering a JLA process, and that might have been useful to look at in a scoping review such as: how much will it cost, how long will the PSP take, and do I need to submit this project to a Research Ethics Board? Did any of the 33 papers address these issues? Regarding the latter, my understanding is that in the UK a JLA process is not considered research, while in Canada it is. This could markedly lengthen the length of time it takes to do a PSP in Canada | Thank for you for this comment. We have added this topic about cost. | See page 33 lines 4-6 |
| #12 | Finally, I note that the reference for Barnieh (reference 33) is the wrong one. The reference describing | Thank you. As we see is these two different studies. | See table 2, Barnieh reference 22 and Manns B reference 19 |

| | the results of that PSP is published | Both studies are | |
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| | with Manns B as the first author in Clin | included. | |
| 1 | J Am Soc Nephrol in 2014. | moluucu. | |
| # | Reviewer: 3 | Authors comments | Page, line |
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| | Please leave your comments for the authors below This is a clearly written, | Thank you, we | |
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| | findings. This point could be made in | | |
| 11.4 | the limitations. | The classic | Daniel Oliver 4 O |
| #1 | The first line of the abstract conclusion | Thank you for your | Page 3 lines 1-3 |
| | would be improved and reflect the | recommendation. We | |
| | study findings more closely if it was | have amended. | |
| | replaced with the first line of the main | | |
| | conclusion: JLA-based PSP makes a | | |
| | useful contribution to identifying | | |
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| | workshop at which a top 10 list of priorities is agreed upon". I suggest this paper would benefit from describing the characteristics of the PSPs, elaborating on aspects they may have operationalized the JLA methods differently (e.g., in gathering and verifying uncertainties), and then offering some analysis (e.g., making recommendations for reporting and/or identifying gaps for research). | | |
|----|---|--|--|
| #2 | MAJOR ISSUES: Objective and questions: The objective of the scoping review, as stated in the paper on page 5 (line 35): "this scoping review describes the JLA approach to the PSP process and how it is used to identify treatment uncertainties and develop top 10 priority lists". With this description, it is unclear how this scoping review differs from the JLA PSP guidebook: http://www.jla.nihr.ac.uk/jla-guidebook/ | Thank you for noticing. This is amended. | See page 6 lines 3-23 |
| #3 | Some of the questions guiding the review should be refined. For example, page 5 (line 42), lists question 1 as "What characterizes adherence to the JLA approach?"; these are all JLA PSPs, so presumably they all adhere to the JLA approach. | Thank you for the comment. This is amended | See page 5 lines 6 lines 3-23 |
| #4 | This also makes the meaning of "if the JLA guidelines were used" statement (page 8, line 27) unclear. | Thank for this comment. This is amended. | See page 9 line 10 |
| #5 | Also, page 5 (line 47), lists question 2 as "How are PSPs organized?"; this is vague and, therefore, it's unclear if it is ever answered. | Thank for noticing this. This is amended. | See page 5 lines 23-24 + page 6 lines 1-19 |

| #6 | Conversely, page 5 (line 49), question 3 is posed clearly and presents a question that could provide important context and analysis on the PSP process: "What processes are used to gather and verify uncertainties?". | Thank you for the comment. See amended line in the document. | See page 5 lines 23-24 + page 6 lines 1-19 |
|----|---|--|--|
| #7 | In the discussion, the authors focus much attention on how few studies have explored ways to reach vulnerable groups; this is an important point to cover, so could it have been formulated into a question for the scoping review? | Thank you for the feedback. We have changed the question for the scoping review and added a question to user groups which might include that. We have added more information about ethnic and socioeconomic groups | Page 23 lines 15- 19 + page 6 lines 11-12 |
| #8 | Methods: it is not always clear how many reviewers were involved in each phase of study selection. Also, as a scoping review, it is unclear why other sources were not consulted, and in particular, the JLA coordinating centre or website (see comments under "limitations" below). | Thank you for noticing. This is hopefully more clear now. Amendments are made. | See page 8 lines 11-14 |
| #9 | Results: The main table is 12 pages long and quite text heavy, so it would be helpful if the information in the first paragraph of the results (page 21, lines 11-45) were summarized in a | Thank you for this comment. We have deleted some text in the table. | |
| | Also, the results are not fully aligned with the research questions. As an example, on page 21, line 35: "compared with clinicians, patients and carers contributed a greater number of questions regarding psychosocial issues, psychosocial stress, depression and anxiety" - was distribution of questions by respondent | Thank you for noting. We agree with this comment. Amendments are made. Research questions are reworded. | See page 23 lines 22-23 + page 6 lines 11-12 |
| | distribution of questions by respondent type part of the data extraction? (it is not typically reported as the JLA is designed to identify shared research priorities). This is also mentioned in the discussion (page 25, line 50). | Thank you for the comment. We have deleted the sentence. | See page 28 lines 24-25 + page 29 lines 1-2 |

| #10 | Although question 3 states "what processes are used to gather and verify uncertainties", neither is reported in table 2 and I can't see that methods for verifying uncertainties was addressed. | Thank you for noting. This is amended. | See page 25 lines 24-25 |
|-----|---|--|---|
| #11 | Limitations: Although they identify limitations to the JLA process (in the article summary), the authors do not discuss limitations to their scoping review except to say that: (1) they may not have identified all relevant studies and (2) they did not search the grey literature because they assumed "research using the JLA approach would be found in indexed databases". Limitation (1) could have - and probably should have - been addressed by contacting the James Lind Alliance coordinating centre; they track outcomes of the PSPs and, therefore, likely could have been involved in checking the completeness of the author's reference list - or the authors could have checked the JLA website which lists all PSPs. Limitation (2) is important in this context; PSPs sometimes produce peer reviewed papers and sometimes also/instead produce more detailed reports available through partner organisations (i.e., grey literature). Again, the JLA coordinating centre/website may have assisted with identifying these resources. However, if this was outside the scope of the review, this should be acknowledged as a limitation. | Thank you for your comment. This is amended. | See page 3 lines 18-19 + page 7 lines 10-11 |
| #12 | Finally, another related limitation is that, for some papers, the JLA methods may not have been described in detail because the authors chose to instead reference the detailed JLA guidebook; in other words, the JLA methods may have been followed closely but not fully reported in the published papers (which are limited in word count). | Thank you for this comment. | See page 27 lines 21-22 |

| #13 | As just one example, page 25 (line 14) notes "Nineteen of the studies used the NGT in the final priority setting workshop" – it is likely more (or all) did, but some did not explicitly state it. Conclusions: the conclusions could be better aligned with the questions guiding this scoping review. MINOR ISSUES: | This is amended. Thank you for noticing this. This conclusion is amended. Thank you for this | See page 33 lines 11-14 See page 4 lines |
|-----|---|---|---|
| | Page 4, line 12: implies PPI is achieved "through discussion" but, in fact, patients and public are sometimes more involved than that (e.g., patients have been involved in data collection, dissemination, etc.) | comment. This is amended. | 11-12 |
| #15 | Page 4, line 19: authors could acknowledge that although PPI has numerous proposed advantages, but evidence is still relatively limited | Thank you for noticing. This is amended. | See page 4 line 16 |
| #16 | Page 5, line 8: "JLA provides independent facilitation and guidance in the identification and prioritization processes" – the JLA provides facilitation and guidance throughout the PSP | Thank you for the comment. This is amended. | See page 5 lines 7-8 |
| #17 | Page 26, line 10: the statement "authors of these studies argue that many basic research endeavours do not lead to results that are useful to the end-user" should be referenced | Thank you for noticing that. We have already deleted the sentence since it is not in accordance in our included studies. | See page 26 lines 24-25 + page 27 lines 1-2 |
| #18 | Page 26, line 15: it's not clear how the results of this scoping review can be interpreted as finding "mismatch between the treatments that patient and clinicians want to have evaluated and the treatments actually being evaluated by the researchers." | Thank you for the comment. We have deleted the sentence | See page 28 lines 24-25 + page 29 lines 1-2 |
| #19 | Page 28, line 17: is reference 46 about patient engagement/PSPs? | Thank you for noticing this. You are totally right. Ref 46 is not about patient engagement but what motived to participant in research. We deleted the reference. | See page 30 lines lines 24-25 + page 31 lines 1-5 |

| #20 | Page 34, line 45: in context of other | Thank you for the | See figure 1 |
|-----|--|-------------------|--------------|
| | exclusions being "not PSP" and "not | comment. | |
| | JLA", what does exclusion "not top 10" | Amended is made. | |
| | mean? | | |
| | | | |

VERSION 2 - REVIEW

| REVIEWER | Jennifer Bethell KITE, Toronto Rehabilitation Institute, University Health Network |
|-----------------|--|
| REVIEW RETURNED | 01-Jul-2019 |

GENERAL COMMENTS From my previous review, I had noted that the questions guiding the scoping review could be refined (#3, #5, #6, #7) and the conclusions could be better aligned with the questions (#13); but it seems like the authors have interpreted this by removing all the research questions, adding methods (data items) details to the introduction and repeating results in the conclusions. My comments may have been unclear (and these should be relatively minor edits) so hopefully this reference will be helpful instead: https://annals.org/aim/fullarticle/2700389/prisma-extensionscoping-reviews-prisma-scr-checklist-explanation Results (Page 23, line 20-21): "Compared with clinicians, patients and carers contributed a greater number of questions on psychosocial issues, psychosocial stress, depression and anxiety" and this point is repeated in methods (page 28, lines 13-17). I am still unclear on the meaning of this statement, particularly since PSPs are designed to identify shared research priorities; it would be unusual to report priorities/questions stratified by source (i.e., patient/carer vs. clinicians). It would be good to know if the authors extracted this information for all the studies (i.e., whether the paper presented stratified lists of priorities/questions)? If yes, how many? Is this interpretation based on only three studies? In my previous review I noted that not all papers would detail every aspect of the JLA methods and instead reference the JLA guidebook (as a strategy to keep within journal word limits). One example was given to illustrate this point, but the authors have only addressed the specific example (not the overarching issue or its implications for their findings). It seems like the strengths and limitations of this study (page 3. lines 8-19) mostly lists/summarizes findings from the review and aspects of the JLA PSP process - not strengths and limitations of

the current scoping review.

VERSION 2 – AUTHOR RESPONSE

Thank you to the reviewer 4 for valuable comments and recommendations. We have followed the suggestions.

| Numbers | Reviewers comments | Authors comments | Page, line |
|---------|---|---|---|
| | Reviewer: 4 | | |
| # 1 | From my previous review, I had noted that the questions guiding the scoping review could be refined (#3, #5, #6, #7) and the conclusions could be better aligned with the questions (#13); but it seems like the authors have interpreted this by removing all the research questions, adding methods (data items) details to the introduction and repeating results in the conclusions. My comments may have been unclear (and these should be relatively minor edits) so hopefully this reference will be helpful instead: https://annals.org/aim/fullarticle/2700389/prisma-extension-scoping-reviews-prisma-scr-checklist-explanation | Thank you, we agree with these comments. This is amended. We have revised the research questions: •How do the studies describe the characteristics of the PSPs, and elaborating on aspects how they have operationalized the JLA methods? •How do the studies describe involvement of different user groups? •What processes are used to gather and verify uncertainties Conclusions is amended as well: Finally, it is important that the results of these studies, including the Top 10 priorities, reach those who answered the | Please see page 6 lines 7-10, page 32 lines 14-16 and page 32 lines 21-22 |

| #2 | Results (Page 23, line 20-21): "Compared with clinicians, patients and carers contributed a greater number of questions on psychosocial issues, psychosocial stress, depression and anxiety" and this point is repeated in methods (page 28, lines 13-17). I am still unclear on the meaning of this statement, particularly since PSPs are designed to identify shared research priorities; it would be unusual to report priorities/questions stratified by source (i.e., patient/carer vs. clinicians). It would be good to know if the authors extracted this information for all the studies (i.e., whether the paper presented stratified lists of priorities/questions)? If yes, how many? Is this interpretation based on only three studies? | survey, including the vulnerable groups. We recommend publishing online to give all the participants in the JLA project easy access to the publications. Thank you for this comment. We agree. This is amended. We want to point out that these three studies described that patient and carers submitted more questions on psychosocial issues, psychosocial stress, depression and anxiety than clinicians, but no studies described disagreement in the prioritization stages. | Please see page 23 lines 14-18 and page 28 line 14-15 |
|-----|---|--|--|
| #3 | In my previous review I noted that not all papers would detail every aspect of the JLA methods and instead reference the JLA guidebook (as a strategy to keep within journal word limits). One example was given to illustrate this point, but the authors have only addressed the specific example (not the overarching issue or its implications for their findings). | Thank you for this comment. We have included a short statement in the discussion. | For details, please see table 2, pages 10-22 as well as page 28 lines 6-8 |
| # 4 | It seems like the strengths and limitations of this study (page 3, lines 8-19) mostly lists/summarizes findings from the review and aspects of the JLA | Thank you for this comment. This had been | Please see page 3 lines 6-20 |

| PSP process - not strengths and limitations of the | changed and | |
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| current scoping review. | we hope it is | |
| | now more | |
| | understandable | |
| | and represent | |
| | strength and | |
| | limitations of | |
| | the current | |
| | scoping review. | |
| | | |

VERSION 3 - REVIEW

| REVIEWER | Jennifer Bethell KITE Toronto Rehab University Health Network |
|-----------------|--|
| REVIEW RETURNED | 12-Jul-2019 |

| GENERAL COMMENTS | Thank you for addressing review comments. |
|------------------|---|
|------------------|---|