

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Patient engagement in hospital health service planning and improvement: a scoping review
<b>AUTHORS</b>	Liang, Laurel; Cako, Albina; Urquhart, Robin; Straus, Sharon; Wodchis, Walter; Baker, Ross; Gagliardi, Anna

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Dr Carla Saunders University of Technology Sydney
<b>REVIEW RETURNED</b>	16-Aug-2017

<b>GENERAL COMMENTS</b>	<p>Thank you for the work on this important and growing field. My comments are intended to support academic writing skills and a better understanding of research and writing for this field:</p> <ul style="list-style-type: none"><li>- Please do not use acronyms in the abstract. The purpose of an abstract is to provide a clear summary of the research. The subject matter also calls for the use of clear plain language wherever possible. Where this is not possible, an explanation of highly technical terms is warranted.</li><li>- Please identify in a clear and consistent manner a single aim/purpose of the research. Currently there are 3 or more different aims/purpose. In the abstract you state "The purpose of this research was to characterize primary research on PE in hospitals.", which is vague at best. In the first dot point of the strength and limitations you state "characteristics of research on how to engage patients in hospital service planning and improvement". In the background the purpose is given as "The purpose of this study was to synthesize primary research on PE in hospital health service improvement and describe the characteristics of those studies, and approaches, interventions and conditions conducive to PE in the hospital context." In the first sentence in the methods section you state "This review sought to describe research on the variety of ways in which patients have been engaged in hospital health service improvement."</li><li>- In the results section, the same information is repeated in the text and tables, please amend.</li><li>- In the results you have subsections that relate to PE evaluation and impact which is not made clear as a purpose of the research, nor is it evident in the search terms e.g. the word outcomes or impact were not included. This may be why you did not find anything in relation to these areas.</li><li>- A key concern of this paper as written is the neglect of the broader context in relation to this field.</li></ul>
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	<p>Much more emphasis should be given to the limitations in relation to the narrowness of this study and the actual reality.</p> <p>For example, three words are given that grey literature was not investigated. The exclusion professional grey literature which is known to be where most useful information on this field can be found, including professional websites and organizations dedicated to this field that provide rigorous evaluative research reports, validated assessment instruments, large data-sets (that allow an almost real-time understanding and an ability to monitor trends), and much more, is misleading.</p> <ul style="list-style-type: none"> <li>- Also misleading is the absence of a declaration that in many countries consumer or patient engagement has become common place in health services and the absence of academic studies reporting the results of patient experience surveys and subsequent improvement efforts that result from this feedback.</li> <li>- It is becoming much more of an imperative to give full and frank consideration of any research project and it's likely importance within the full context of current understanding on an issue before it is undertaken. We can no longer afford convenient or practice research, especially research or publication that has the potential to 'muddy the waters' rather than advance our understanding of an important area. If the aim of the research was to bring attention to the field I do not think it has done it justice, particularly in terms of providing accurate information on the current state of play or the growing focus the field has actually been given in recent years.</li> </ul>
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<b>REVIEWER</b>	Taya Irizarry University of Pittsburgh, USA
<b>REVIEW RETURNED</b>	24-Sep-2017

<b>GENERAL COMMENTS</b>	<p>This paper described the finding of a scoping review focused on research about patient engagement in health service improvement in the hospital setting. For the most part, the writing is clear and the manuscript is well organized. The following suggestions aim to clarify a few instances where the aim of the study is unclear and to strengthen the rigor of the methods section. In doing so, I believe this manuscript will be a welcome addition to literature in the arena.</p> <p>Major comments:</p> <p>1a) The purpose stated in the abstract is not fully elucidated, it was until I read through the background section and methods that I realized that the purpose of the work was to review literature having to do with PE defined as patients involved in design and improvement of health services. The abstract reads “The purpose of this research was to characterize primary research on PE in hospitals.” The end of the background section reads “The purpose of this study was to synthesize primary research on PE in hospital health service improvement and describe the characteristics of those studies, and approaches, interventions and conditions conducive to PE in the hospital context.” The second statement is much more clear and specific, I would use it in the abstract as well.</p> <p>1b) On a related topic, there a number of places throughout the text where it is not clear that you are specically talking about PE in health services improvement instead of PE at the individual care level.</p>
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For example, the statement page 10: "No studies developed or evaluated behavioural interventions that would promote or support PE by influencing patient or provider beliefs or actions." I would clarify that you're specifically talking about PE defined as participating in service improvement since there are numerous interventions that seek to improve patient engagement in their healthcare at the individual level. The discussion section has numerous statements that could be clarified in this way as well.

2) Background page 4, line 22- it is not clear that the strategies described here refer to the out-patient setting. It would be helpful to know this up front. As it is written now it seems like what's written should be something you would discuss in the results section of the paper instead of the background, especially after reading the results section of the abstract since many of same themes are mentioned. It would make more sense if you started the paragraph with something about how what we know about implementing PE strategies is based on research in the outpatient setting (basically your sentence on line 39). Then go into, For example...that way it's clear that you're not talking about the findings of your study and clearly underscores what is known is only known in the outpatient setting up front instead of waiting to tell the reader in the last paragraph.

3) Methods section page 5 line 14, the discuss about the search terms was vague. It is helpful in a literature review to include all search terms so that a reader could replicate the search. If the search terms are too numerous, I suggest including them in a list in the appendix.

4) Page 7 line 20-I'm not sure it's clear what the point of aggregating 8 studies' sample size. A range and average would be more helpful. "Among 8 eligible studies, participants included 87 patients and 322 providers; another study included 126 participants but did not report the number of patients and providers; [20] and another study did not report the total number of participants.[26]"

5) Table 2 is redundant- it states what is in the text verbatim. Consider removing it, or keep it and include only a summary of it in the text and then reference it.

Minor comments:

1) Abstract (line 7) "Most PE research was based on primary care." Using past tense is less clear, I recommend changing it "is" instead of was.

2) Abstract Results: first sentence (line 21) "Of 3,939 published reports identified, 3,914 were unique, and 3,690 were excluded." is not necessary information and distracts from the real message, such detail is appropriate for the body of the paper. Just stating the number of full text articles screened is enough for the abstract.

3) Last sentence of abstract results: "Asking patients to provide insight on problems rather than solutions, and provider champions may enhance patient influence on hospital services." I think there is a word missing after "and", perhaps the inserting a word like identifying or implementing would help?

<b>REVIEWER</b>	Nathaniel Thomas Warren OCHIN, Inc., United States
<b>REVIEW RETURNED</b>	26-Sep-2017

<b>GENERAL COMMENTS</b>	<p>The authors' provide a strong manuscript in the field of patient engagement. The scoping review definition was helpful for those unfamiliar and seems appropriate for this topic and the manuscript's aims. A revision consideration of expanding scoping search criteria to "stakeholder participation" and "citizen participation" as well as "engagement" with the consumer/patient/stakeholder/citizen qualifiers may extend the applicable data (unless already included). Regarding the search strategy, in the screening of systematic reviews, while not eligible for inclusion, a helpful option on potential additional eligible primary studies may be from Domecq et al. in BMC Health Services Research, 2014.</p> <p>Under the "Type of PE" section, potentially expanding on "Little detail was provided about precisely what patients were meant to do or did in relation to these activities" could be helpful for future projects' methods (e.g. interview protocols, patient engagement role descriptions). What was missing? What would be a more comprehensive level of detail?</p> <p>Table 1 provides a helpful scale of PE activities as a guidance framework in the aggregate. In regards to the study description, I found it of great utility to see the expansion on the reasons for PE barriers, especially from the study quoted below: "In another study, observation of 21 planning committee meetings across 5 sites found that patients attended but were largely silent, and both patients and providers agreed patients were not effectively involved in meetings as partners and their suggestions were ignored." Providing thematic results was a great addition (e.g. power differentials, unclear expectations, ineffective resourcing).</p> <p>In the Conclusions period, for the following statement, similar to the Type of PE section an expansion on this might be beneficial: "Few studies were eligible and those studies provided few specific details about what patients were meant to do or actually did." What was missing? What would be a more comprehensive level of detail?</p> <p>Within the Discussion section, the mechanisms of successful providers is an important outcome and it may be helpful in expanding on this (perhaps similar to the rubric in Table 2) by further identifying both the facilitators and barriers to successful provider roles in PE work.</p> <p>A final question from the Conclusion section was whether the authors found in any of the literature if the timing of PE activity requests in relation to the project deadlines had an impact on successful engagement? For instance, if a marketing campaign sought out PE review but did not budget adequate time for implementing changes, this activity may end up "tokenistic" in terms of authentic opportunities to impact the literacy level, images and other aspects of the content.</p> <p>As a next step in ongoing primary research which considers behavioral interventions, are the authors' familiar with or was their any use of the The Patient Activation Measure® (PAM®), assessment as a potential additional tool for consideration?</p>
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<b>REVIEWER</b>	Mariona Pons-Vigués Institut Universitari d'Investigació en Atenció Primària Jordi Gol (IDIAP Jordi Gol), Barcelona, Catalonia, Spain
<b>REVIEW RETURNED</b>	17-Oct-2017

<b>GENERAL COMMENTS</b>	<p>This paper faces an important topic in public engagement. It is a legal right that is based on social justice, empowerment and autonomy. The objective is to synthesize primary research on Patient Engagement (PE) in hospital health service improvement and describe the characteristics of those studies, and approaches, interventions and conditions conducive to PE in the hospital context. The objective of the study is clearly defined in the background. Please, the aim of the scoping review should be specified in more detail in the abstract.</p> <p>As the importance of public engagement is growing, the literature search, restricted to the most common scientific websites, is an away too old (September 2016) and some others paper could have been published on the same topic in the last year.</p> <p>The methods for carrying out the scoping review appear to be appropriate. The methodology used, with independent researchers carrying out different stages of the mapping and review process, is described in detail. However, I have some questions: Why are providers included? Why are child and adolescents excluded? In my point of view, it would be more interesting to include only patients (adult and child population). Please, justify in more detail these criteria.</p> <p>Although quality of studies is not customary for a scoping review, it would be interesting to assess the risk of bias in all the included studies. In addition, it would be interesting to detail the reason for the exclusion of 3634 papers (titles and abstract screening).</p> <p>Please, add the variable “type of PE activities” (consultation, involvement, partnership and Shared leadership) and risk of bias in the table “Additional File 1. Data Extracted from included studies”.</p> <p>As the authors explain in the discussion, grey literature and non-English studies are two important limitations. Although the combination of heterogeneous sources of data were included, there are probably some documents describing PE in hospitals which have not been collected in this scoping review because they are in the grey literature or publish in another language. Please, could you discuss and quantify these two limitations in more detail?</p>
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### VERSION 1 – AUTHOR RESPONSE

REVIEWER #1 (Carla Saunders)

1/

Thank you for the work on this important and growing field. My comments are intended to support academic writing skills and a better understanding of research and writing for this field

AUTHORS

Thank you!

2/

Please do not use acronyms in the abstract. The purpose of an abstract is to provide a clear summary of the research. The subject matter also calls for the use of clear plain language wherever possible. Where this is not possible, an explanation of highly technical terms is warranted

#### AUTHORS

The abstract used the acronym PE for patient engagement. We replaced every instance of "PE" with "patient engagement". To maintain the word limit for the abstract and remove additional acronyms we also changed "MEDLINE, EMBASE, CINAHL, HealthStar and the Cochrane Library were searched..." to "Five databases were searched..."

3/

Please identify in a clear and consistent manner a single aim/purpose of the research. Currently there are 3 or more different aims/purpose. In the abstract you state "The purpose of this research was to characterize primary research on PE in hospitals.", which is vague at best. In the first dot point of the strength and limitations you state "characteristics of research on how to engage patients in hospital service planning and improvement". In the background the purpose is given as "The purpose of this study was to synthesize primary research on PE in hospital health service improvement and describe the characteristics of those studies, and approaches, interventions and conditions conducive to PE in the hospital context." In the first sentence in the methods section you state "This review sought to describe research on the variety of ways in which patients have been engaged in hospital health service improvement."

#### AUTHORS

We agree that the purpose could be more clearly and consistently stated. The Background (page 4) now states: "The primary purpose of this study was to describe the characteristics of peer-reviewed empirical research that evaluated PE in hospital health service improvement. In so doing, we also sought to describe the types, extent, determinants, interventions and impact of PE in the hospital context."

Accordingly, the Abstract, Objectives (page 3) now states: "The primary purpose of this study was to describe the characteristics of published empirical research that evaluated PE in hospital health service improvement."

To avoid repetition and conform to the manuscript word limit, in Methods, Approach (page 4) we eliminated: "This review sought to describe research on the variety of ways in which patients have been engaged in hospital health service improvement. Therefore," This section now begins: "Rather than a traditional systematic review..."

The first bullet point of the Strengths and Limitations (page 3) now states: "By describing the characteristics of peer-reviewed empirical research that evaluated PE in hospital health service improvement, this research identified what is known about how to achieve PE in hospital health service improvement and, in so doing, exposed gaps in knowledge that inform future research in this area."

4/

In the results section, the same information is repeated in the text and tables, please amend

#### AUTHORS

We agree that data should not be completely replicated in the Results text and tables/figures. Yet a balance must be achieved in providing some written summary of the data that appears in tables, particularly for tables available online only. We examined each section of the written Results to assess where we could remove text and rely on readers to acquire information from Tables/Figures while at the same time ensuring that we complied with PRISMA reporting standards and retained content considered essential by three other peer reviewers of this manuscript. As a result, we amended the Results (page 7-10) as follows. However, if the reviewers and editors feel there is material that should be deleted to enhance readability, we would be happy to consider their further suggestions.

#### Search results

As Figure 1, the PRISMA diagram, summarizes similar information and is included directly in the manuscript, we further synthesized this section to: "From a total of 3,939 search results, 276 full-text studies emerged as potentially relevant, of those 214 did not meet eligibility criteria, and 10 studies were included in the review (Figure 1)."

#### Study characteristics

This section remains unchanged because it is a synthesis of data that appears in Supplementary File 2, which is available online only, and readers may not refer to it and, if they did, could not readily deduce this information.

#### Type of PE

This section remains unchanged. The first paragraph is a synthesis of data that appears in Supplementary File 2. As noted above, readers may not refer to the online only file. The second paragraph synthesizes the somewhat more detailed information that appears in Table 1, which is readily available in the manuscript, but this paragraph is very brief.

#### Extent of PE

Unchanged, synthesis of data from Supplementary File 2, and readers may not refer to the online only file.

#### Factors influencing PE

Another peer reviewer also noted that this section duplicates Table 2. We retained Table 2 and further synthesized this section to: "Seven studies (70.0%) assessed facilitators or barriers to PE (Table 2). Of the 10 distinct barriers identified, most pertained to providers including negative beliefs and attitudes about patient roles and input, lack of knowledge and skills, hierarchies and dysfunction among providers, and uncertainty about how to resolve differing patient and senior management priorities. Of the 10 distinct facilitators, most pertained to processes that optimize PE such as formalizing patient roles, small team size, frequent meetings, active solicitation of patient input, and debriefing after meetings."

The brief paragraph about mechanisms following Table 2 was retained because it summarizes data from Supplementary File 2, and readers may not refer to the online only file.

#### PE interventions

Brief so retained

#### PE impact

Unchanged because it summarizes data from Supplementary File 2, and readers may not refer to the online only file.

In the results you have subsections that relate to PE evaluation and impact which is not made clear as a purpose of the research, nor is it evident in the search terms e.g. the word outcomes or impact were not included. This may be why you did not find anything in relation to these areas.

#### AUTHORS

As noted above, we modified the purpose in the Background to read: "The primary purpose of this study was to describe the characteristics of peer-reviewed empirical research that evaluated PE in hospital health service improvement. In so doing, we also sought to describe the types, extent, determinants, interventions and impact of PE in the hospital context."

With respect to the search strategy (Supplementary File 1), one achieves a better balance of sensitivity and specificity if Medical Subject Headings (MeSH) are used, if they are available and closely match the desired concepts, instead of keywords. For our search, the following MeSH terms pertaining to outcomes or impact or any research of any kind that evaluated PE were available: Health Services Research, Program Evaluation, Quality Assurance, Quality Improvement, Quality of Health Care, Research, Behavioral research, Operations research, or Research design. These terms combined retrieved a total of 172,660 results. The principal investigator is a trained medical librarian and worked with another trained medical librarian to optimize the search strategy, which also complied with the Peer Review of Electronic Search Strategy reporting guidelines. We are confident that the search strategy was robust, and that included studies were few because there is little peer-reviewed research on PE for hospital service improvement.

6/

A key concern of this paper as written is the neglect of the broader context in relation to this field. Much more emphasis should be given to the limitations in relation to the narrowness of this study and the actual reality. For example, three words are given that grey literature was not investigated. The exclusion professional grey literature which is known to be where most useful information on this field can be found, including professional websites and organizations dedicated to this field that provide rigorous evaluative research reports, validated assessment instruments, large data-sets (that allow an almost real-time understanding and an ability to monitor trends), and much more, is misleading.

#### AUTHORS

Establishing the purpose and eligibility criteria of any systematic review represents a balance – too broad and the issue cannot be assessed in depth, too narrow and the topic is not sufficiently addressed. The study parameters chosen were quite broad:

- Overall purpose was broad – to describe studies that evaluated engagement of patients in any hospital health service
- Eligibility criteria were broad:
  - o Any adult patients and any type of provider (clinician or manager)
  - o Hospitals in any setting (a study from Uganda was included)
  - o PE included governance, planning, delivery, evaluation, quality improvement or research (i.e. anything other than engagement in their own care)
  - o Outcomes included any reported in the eligible studies
  - o Any type of empirical study design (quantitative or qualitative)
- The fact that only 10 studies were eligible despite broad eligibility criteria underscores the paucity of peer-reviewed research on this important topic, which addresses the purpose of a scoping review, to identify gaps in knowledge that warrant ongoing research

We chose not to include grey literature for the following reasons:



- A key reason for doing a scoping review is to describe the nature of empirical research on a given topic. As this reviewer noted, grey literature largely offers instruments, data sets, and various types of reports that may not be empirical research; therefore, to optimize yield, we searched the standard indexed research databases only; moreover, research conducted by professional organizations that is of a rigorous nature is generally published in the peer-reviewed literature and would likely have been identified by our search of indexed databases
- Grey literature has been described by others (who we now cite, see below) as difficult, time-consuming with low yield, there are no gold standards for systematic grey literature searching methods plus evaluations found in grey literature and grey information may be at high risk of bias for a number of reasons; hence, it is not a mandatory requirement of scoping reviews
- Grey literature searching also includes contacting key informants for referrals to relevant information further adding to the time-consuming nature – it has been compared to primary research. Thus, it is highly dependent on the availability of resources. We had no funding for this research and relied on two students to help us complete this work. Given the low yield and limited resources, grey literature searching was not feasible.

In the original manuscript we explicitly acknowledged the lack of grey literature searching as a limitation. But, to elaborate on this issue, we did the following to provide more explanation for this decision:

- Methods, Eligibility criteria (page 5): “Eligible study designs included...qualitative...or quantitative...or mixed methods studies published in peer-reviewed journals.”
- Methods, Searching (page 6): “We did not search grey literature because it is time-consuming and costly with low yield, and not feasible given that we had few resources for this study; there are no standard methods for doing so, and grey information may be at high risk of bias.[18,19]”
- Discussion, Limitations (page 11): “We did not search the grey literature given the methodological challenges that have been identified by others.[18,19]”

7/

Also misleading is the: (1) absence of a declaration that in many countries consumer or patient engagement has become common place in health services, and (2) the absence of academic studies reporting the results of patient experience surveys and subsequent improvement efforts that result from this feedback.

## AUTHORS

The purpose of our scoping review was to describe the characteristics of peer-reviewed empirical research that evaluated PE in hospital health service improvement. The purpose of our scoping review was not to synthesize research on the implementation and use (i.e. prevalence) of patient engagement. However, we did explicitly state that patient engagement in their own care, and at the organizational level for health service planning and improvement has become “a worldwide priority because evidence shows that it improves numerous patient outcomes such as satisfaction with care received, and health system outcomes such as cost-effective service delivery.

[1,2]” The Background (page 4) describes patient engagement strategies that have been used and challenges in doing so, leading to token PE and limited impact on health service improvements. Hence, the need for this scoping review to assess if research has examined how to optimize PE for hospital health service improvement.

The purpose of our scoping review was to describe the characteristics of peer-reviewed empirical research that evaluated PE in hospital health service improvement. As noted in Methods, Eligibility criteria (page 5) this referred to “included consulting about or engaging patients or providers in hospital health service improvement activities of any type including governance, service planning, delivery, evaluation or quality improvement, or research to inform service design or improvement.”

Research on patient experience and instruments used to collect data on patient experience is related, but reflects patient evaluations of hospital services or clinical care received, which is an entirely separate body of literature, and was out of scope for this review unless patient experience was measured and reported as a long-term outcome of patient engagement in hospital health service planning. None of the 10 included studies reported patient experience. Instead, a single study reported more immediate outcomes of patient engagement directly related to engagement activities such as perceived effectiveness of meetings. To clarify, we modified Methods, Eligibility criteria (page 5): “Studies were not eligible if they.... reported evaluations of patient satisfaction or experience with clinical care.”

8/

It is becoming much more of an imperative to give full and frank consideration of any research project and it's likely importance within the full context of current understanding on an issue before it is undertaken. We can no longer afford convenient or practice research, especially research or publication that has the potential to 'muddy the waters' rather than advance our understanding of an important area. If the aim of the research was to bring attention to the field I do not think it has done it justice, particularly in terms of providing accurate information on the current state of play or the growing focus the field has actually been given in recent years.

#### AUTHORS

We agree that more clarity needs to be brought to this area of research; hence, we undertook this scoping review to focus on PE in hospital service improvement and reveal the current state of research on this topic, thereby revealing what is known and not known, and establishing a basis for further research where gaps were revealed. To ensure that we clarified the results, we abbreviated the Results as mentioned in our response to this reviewer's fourth comment, and focused the Discussion on the critical gaps in this research area. The findings clearly show that, despite the increasing importance of patient engagement in hospital health service planning and improvement, there is a paucity of empirical peer-reviewed research on how it can be optimized, and we provide several suggestions for ongoing research. Other peer reviewers offered the following comments, emphasizing the value of this study:

- Reviewer #2: “For the most part, the writing is clear and the manuscript is well organized. The following suggestions aim to clarify a few instances...In doing so, I believe this manuscript will be a welcome addition to literature in the arena.”
- Reviewer #3: “The authors' provide a strong manuscript in the field of patient engagement.”
- Reviewer #4: “This paper faces an important topic in public engagement. It is a legal right that is based on social justice, empowerment and autonomy.”

#### REVIEWER #2 (Tanya Irizarry)

1/

For the most part, the writing is clear and the manuscript is well organized. The following suggestions aim to clarify a few instances where the aim of the study is unclear and to strengthen the rigor of the methods section. In doing so, I believe this manuscript will be a welcome addition to literature in the arena.

#### AUTHORS

Thank you!

2/

The purpose stated in the abstract is not fully elucidated, it was until I read through the background section and methods that I realized that the purpose of the work was to review literature having to do with PE defined as patients involved in design and improvement of health services. The abstract

reads “The purpose of this research was to characterize primary research on PE in hospitals.” The end of the background section reads “The purpose of this study was to synthesize primary research on PE in hospital health service improvement and describe the characteristics of those studies, and approaches, interventions and conditions conducive to PE in the hospital context.” The second statement is much more clear and specific, I would use it in the abstract as well.

#### AUTHORS

We agree that the purpose could be more clearly and consistently stated. The Background (page 4) now states: “The primary purpose of this study was to describe the characteristics of peer-reviewed empirical research that evaluated PE in hospital health service improvement. In so doing, we also sought to describe the types, extent, determinants, interventions and impact of PE in the hospital context.”

Accordingly, the Abstract, Objectives (page 3) now states: “The primary purpose of this study was to describe the characteristics of peer-reviewed empirical research that evaluated PE in hospital health service improvement.”

To avoid repetition and conform to the manuscript word limit, in Methods, Approach (page 4) we eliminated: “This review sought to describe research on the variety of ways in which patients have been engaged in hospital health service improvement. Therefore,” This section now begins: “Rather than a traditional systematic review...”

The first bullet point of the Strengths and Limitations (page 3) now states: “By describing the characteristics of peer-reviewed empirical research that evaluated PE in hospital health service improvement, this research identified what is known about how to achieve PE in hospital health service improvement and, in so doing, exposed gaps in knowledge that inform future research in this area.”

3/

On a related topic, there a number of places throughout the text where it is not clear that you are specifically talking about PE in health services improvement instead of PE at the individual care level. For example, the statement page 10: “No studies developed or evaluated behavioural interventions that would promote or support PE by influencing patient or provider beliefs or actions.” I would clarify that you’re specifically talking about PE defined as participating in service improvement since there are numerous interventions that seek to improve patient engagement in their healthcare at the individual level. The discussion section has numerous statements that could be clarified in this way as well.

#### AUTHORS

We scanned the entire manuscript and in numerous places throughout replaced “PE” with “PE for hospital service improvement”.

4/

Background page 4, line 22- it is not clear that the strategies described here refer to the out-patient setting. It would be helpful to know this up front. As it is written now it seems like what’s written should be something you would discuss in the results section of the paper instead of the background, especially after reading the results section of the abstract since many of same themes are mentioned. It would make more sense if you started the paragraph with something about how what we know about implementing PE strategies is based on research in the outpatient setting (basically your sentence on line 39). Then go into, For example...that way it’s clear that you’re not talking about the findings of your study and clearly underscores what is known is only known in the outpatient setting up front instead of waiting to tell the reader in the last paragraph.

## AUTHORS

Background, paragraph two (page 4) now reads: “Research, largely in outpatient settings, has identified strategies that support PE in service improvement; for example, joint training of patients and frontline health care professionals, clearly defined roles and responsibilities, and trained facilitators to coach teams.[10]”

5/

Methods section page 5 line 14, the discussion about the search terms was vague. It is helpful in a literature review to include all search terms so that a reader could replicate the search. If the search terms are too numerous, I suggest including them in a list in the appendix.

## AUTHORS

We provided the final search strategy that was used in Supplementary File 1. This final search strategy will allow others to retrieve the same literature and/or, at some point in the future, update the scoping review.

6/

Page 7 line 20-I'm not sure it's clear what the point of aggregating 8 studies' sample size. A range and average would be more helpful. “Among 8 eligible studies, participants included 87 patients and 322 providers; another study included 126 participants but did not report the number of patients and providers; [20] and another study did not report the total number of participants.[26]”

## AUTHORS

Results, Study characteristics (page 7) now reads: “Eight of 10 studies reported the number of participating patients (range 10 to 20) and providers (range 18 to 142).”

7/

Table 2 is redundant- it states what is in the text verbatim. Consider removing it, or keep it and include only a summary of it in the text and then reference it.

## AUTHORS

We retained Table 2 and further synthesized the written Results, Factors influencing PE (page 9) to: “Seven studies (70.0%) assessed facilitators or barriers to PE (Table 2). Of the 10 distinct barriers identified, most pertained to providers including negative beliefs and attitudes about patient roles and input, lack of knowledge and skills, hierarchies and dysfunction among providers, and uncertainty about how to resolve differing patient and senior management priorities.

Of the 10 distinct facilitators, most pertained to processes that optimize PE such as formalizing patient roles, small team size, frequent meetings, active solicitation of patient input, and debriefing after meetings.”

8/

Abstract Objectives: “Most PE research was based on primary care.” Using past tense is less clear, I recommend changing it “is” instead of was.

## AUTHORS

Done

9/

Abstract Results: first sentence (line 21) “Of 3,939 published reports identified, 3,914 were unique, and 3,690 were excluded.” is not necessary information and distracts from the real message, such

detail is appropriate for the body of the paper. Just stating the number of full text articles screened is enough for the abstract.

#### AUTHORS

This was changed to: "From a total of 3,939 search results, 227 full-text studies emerged as potentially relevant, of those 217 did not meet eligibility criteria, and 10 studies were included in the review."

10/

Last sentence of abstract results: "Asking patients to provide insight on problems rather than solutions, and provider champions may enhance patient influence on hospital services." I think there is a word missing after "and", perhaps the inserting a word like identifying or implementing would help?

#### AUTHORS

We used the word "deploying" so the sentence now reads: "Asking patients to provide insight on problems rather than solutions, and deploying provider champions may enhance patient influence on hospital services."

#### REVIEWER #3 (Nathaniel Thomas Warren)

1/

The authors' provide a strong manuscript in the field of patient engagement. The scoping review definition was helpful for those unfamiliar and seems appropriate for this topic and the manuscript's aims.

#### AUTHORS

Thank you!

2/

A revision consideration of expanding scoping search criteria to "stakeholder participation" and "citizen participation" as well as "engagement" with the consumer/patient/stakeholder/citizen qualifiers may extend the applicable data (unless already included).

#### AUTHORS

We cannot now expand the scope because we no longer have resources for this study; however, the search strategy we employed (Supplementary File 1) was very comprehensive. The principal investigator is a trained medical librarian and worked with another trained medical librarian to optimize the search strategy, which also complied with the Peer Review of Electronic Search Strategy reporting guidelines.

Our search strategy employed keywords for patient, public, family, consumer or user adjacent to the terms with the root engage, involve or participate.

To retrieve articles pertaining to involvement or engagement of consumers, patients, stakeholders, citizens or the same identified by any other label we used Medical Subject Headings. This strategy would have identified articles about PE that only used the terms stakeholder or citizen engagement or participation or any other variant:

Patient-Centered Care/mt, og [Methods, Organization & Administration] (5523)

22 Consumer Participation/ (9801)

23 Patient Participation/ (15899)

3/

Regarding the search strategy, in the screening of systematic reviews, while not eligible for inclusion, a helpful option on potential additional eligible primary studies may be from Domecq et al. in BMC Health Services Research, 2014.

AUTHORS

Thank you very much for bringing this review to our attention. We did look up this article, which focused on patient engagement in research. It would not have been identified by our search strategy because it did not focus on hospitals. In looking at how it was indexed in MEDLINE, we would only have retrieved it using the following Medical Subject Headings: Advisory Committees, Biomedical Research, Humans, Patient Participation, Randomized Controlled Trials as Topic, and Research Subjects. However, it is useful to be aware of it in case we update the scoping review in future and can scan the references for potentially eligible primary studies.

4/

Under the "Type of PE" section, potentially expanding on "Little detail was provided about precisely what patients were meant to do or did in relation to these activities" could be helpful for future projects' methods (e.g. interview protocols, patient engagement role descriptions). What was missing? What would be a more comprehensive level of detail?

AUTHORS

In Results, Type of PE (page 7) we added additional detail to clarify the level and detail of information that was typically not reported in included studies: "For example, a survey of quality managers identified that in 50.0% of hospitals patients were involved in quality improvement projects, and in 64.8% of hospitals patients were involved in quality committees, but the survey did not gather specific information about patient involvement in those initiatives such as mode or frequency of engagement, information they contributed or how it was used.[18] A more informative study involving interviews with nurses and patients on a nurse-led advisory council revealed that patients were involved in a range of activities including commenting on documents, establishing working groups on specific topics and membership on hospital multidisciplinary groups to conduct service.[27]."

5/

Table 1 provides a helpful scale of PE activities as a guidance framework in the aggregate. In regards to the study description, I found it of great utility to see the expansion on the reasons for PE barriers, especially from the study quoted below: "In another study, observation of 21 planning committee meetings across 5 sites found that patients attended but were largely silent, and both patients and providers agreed patients were not effectively involved in meetings as partners and their suggestions were ignored." Providing thematic results was a great addition (e.g. power differentials, unclear expectations, ineffective resourcing).

AUTHORS

Thank you!

6/

In the Conclusions period, for the following statement, similar to the Type of PE section an expansion on this might be beneficial: "Few studies were eligible and those studies provided few specific details about what patients were meant to do or actually did." What was missing? What would be a more comprehensive level of detail?

AUTHORS

This statement appears in the five-bullet Strengths and Limitations section (page 3). The statement was modified to: "Few studies were eligible and those studies provided few specific details about what

patients were meant to do or actually did (e.g. mode or frequency of engagement, information they contributed or how it was used), thus little knowledge was revealed about how to optimize patient engagement in hospital service planning and improvement”

7/

Within the Discussion section, the mechanisms of successful providers is an important outcome and it may be helpful in expanding on this (perhaps similar to the rubric in Table 2) by further identifying both the facilitators and barriers to successful provider roles in PE work.

#### AUTHORS

To Discussion, paragraph beginning “This review identified two mechanisms...” (page 12) we added: “Analysis of facilitators and barriers identified in included studies that pertain to providers offers additional insight on potential ways to prepare and support providers so that they can, in turn, support patients in their PE role. For example, provider-level barriers (e.g. lack of knowledge of how to engage patients, attitudes about PE, hierarchies and dysfunction among providers) suggest that providers require PE training, and senior leaders must ensure that a culture of PE is implemented including infrastructure and processes.”

8/

A final question from the Conclusion section was whether the authors found in any of the literature if the timing of PE activity requests in relation to the project deadlines had an impact on successful engagement? For instance, if a marketing campaign sought out PE review but did not budget adequate time for implementing changes, this activity may end up "tokenistic" in terms of authentic opportunities to impact the literacy level, images and other aspects of the content.

#### AUTHORS

Time was not addressed in any of the included studies (see Supplementary File 2).

9/

As a next step in ongoing primary research which considers behavioral interventions, are the authors' familiar with or was their any use of the The Patient Activation Measure® (PAM®), assessment as a potential additional tool for consideration?

#### AUTHORS

Thank you! We added information and a reference for PAM in the Discussion, last paragraph before Conclusions (page 12): “Therefore, further primary research is needed to develop and evaluate behavioural interventions for PE directed at patients and providers informed by the PE barriers and facilitators identified here. Matching of barriers and facilitators to relevant interventions could be informed by taxonomies of behaviour change interventions such as the Expert Recommendations for Implementing Change,[33] or the Effective Practice and Organisation of Care taxonomy,[34] and formal processes for developing behavioural interventions such as Intervention Mapping.[35] Instruments exist to assess patient readiness for PE, for example, the Patient Activation Measure; these could be employed to evaluate the impact of behavioural interventions used to prepare patients for PE. [36]

#### REVIEWER #4 (Mariona Pons-Vigués)

1/

This paper faces an important topic in public engagement. It is a legal right that is based on social justice, empowerment and autonomy. The objective is to synthesize primary research on Patient Engagement (PE) in hospital health service improvement and describe the characteristics of those

studies, and approaches, interventions and conditions conducive to PE in the hospital context. The objective of the study is clearly defined in the background.

AUTHORS

Thank you!

2/

Please, the aim of the scoping review should be specified in more detail in the abstract.

AUTHORS

As noted in response to other peer reviewers, we agree that the purpose could be more clearly and consistently stated. The Background (page 4) now states: "The primary purpose of this study was to describe the characteristics of peer-reviewed empirical research that evaluated PE in hospital health service improvement. In so doing, we also sought to describe the types, extent, determinants, interventions and impact of PE in the hospital context."

Accordingly, the Abstract, Objectives (page 3) now states: "The primary purpose of this study was to describe the characteristics of published empirical research that evaluated PE in hospital health service improvement."

To avoid repetition and conform to the manuscript word limit, in Methods, Approach (page 4) we eliminated: "This review sought to describe research on the variety of ways in which patients have been engaged in hospital health service improvement. Therefore," This section now begins: "Rather than a traditional systematic review..."

The first bullet point of the Strengths and Limitations (page 3) now states: "By describing the characteristics of peer-reviewed empirical research that evaluated PE in hospital health service improvement, this research identified what is known about how to achieve PE in hospital health service improvement and, in so doing, exposed gaps in knowledge that inform future research in this area."

3/

As the importance of public engagement is growing, the literature search, restricted to the most common scientific websites, is an away too old (September 2016) and some others paper could have been published on the same topic in the last year.

AUTHORS

We agree that searches conducted now may identify new articles for inclusion. Currency is an inherent challenge in conducting any type of systematic review. We have not updated the review given that we no longer have resources for the study. However, based on literature up to Sept 2016, there is a clear paucity of research on PE in hospital health service improvement, and it is not likely that a profusion of research on this topic would have been published in a single year.

4/

The methods for carrying out the scoping review appear to be appropriate. The methodology used, with independent researchers carrying out different stages of the mapping and review process, is described in detail. However, I have some questions: Why are providers included? Why are child and adolescents excluded? In my point of view, it would be more interesting to include only patients (adult and child population). Please, justify in more detail these criteria.

AUTHORS



Providers were included because research shows that PE is more likely when providers are trained for, and also engaged in PE (see Background, paragraph two, page 4). We now justify including providers in Methods, Eligibility criteria (page 5): “Providers were included because research shows that PE is more likely when providers are trained for, and also engaged in PE.[10-12]”

Adult patients were included because the engagement of children and youth would also require the engagement of their parents, a scenario that differs from the engagement of adult patients and that would likely require PE processes that differ from those for adult patients. While important, given the differing scenario and processes, engaging children and youth in PE is beyond the scope of this review and best addressed in a separate review. We now rationalize this decision in Methods, Eligibility criteria (page 6): “Studies were not eligible if they involved providers not based in hospitals, or more than half were trainees such as interns, residents or fellows; assessed PE in their own care or PE in health service improvement not based in hospitals; or reported evaluations of patient satisfaction or experience with clinical care. Studies involving the engagement of children and youth, thereby necessitating the involvement of parents or surrogates, were not included as PE processes would differ from those required for adults. While important, given the differing scenario and processes, engaging children and youth in PE is beyond the scope of this review and best addressed in a separate review.”

5/

Although quality of studies is not customary for a scoping review, it would be interesting to assess the risk of bias in all the included studies. In addition, it would be interesting to detail the reason for the exclusion of 3634 papers (titles and abstract screening).

#### AUTHORS

As noted in our manuscript and by this reviewer, scoping reviews do not assess risk of bias of included studies because the primary purpose is to describe the nature of research on a given topic. In contrast, a traditional systematic review synthesizes common outcomes across included studies, thus assessment of risk of bias is crucial to determine the validity of the findings. This scoping review included 4 qualitative case studies, 3 qualitative interviews and/or focus groups, and 3 cross-sectional surveys. While reporting standards do exist (i.e. COREQ) by which to assess qualitative research, the focus of those standards is not on assessing risk of bias.

It is customary to detail reasons for exclusion of any full-text articles that were considered. It is quite atypical to detail reasons for exclusion at the stage of title and abstract screening because the reason that applies to the vast majority of discards is generally “not relevant in any way” so the time and effort required to detail specific reasons for thousands of titles would not yield useful information.

In addition to the above reasons, we no longer have resources for this study, and are not able to assess the risk of bias or detail the reasons for exclusion of titles.

6/

Please, add the variable “type of PE activities” (consultation, involvement, partnership and Shared leadership) and risk of bias in the table “Additional File 1. Data Extracted from included studies”.

#### AUTHORS

As suggested, we added a column labelled “Types of PE activities” to Additional File 2 and added data to this column similar to that which appears in Table 2. We did assess risk of bias and therefore did not add a column for this data.

7/

As the authors explain in the discussion, grey literature and non-English studies are two important limitations. Although the combination of heterogeneous sources of data were included, there are probably some documents describing PE in hospitals which have not been collected in this scoping review because they are in the grey literature or publish in another language. Please, could you discuss and quantify these two limitations in more detail?

#### AUTHORS

As noted in response to a previous reviewer, we chose not to include grey literature for the following reasons:

- A key reason for doing a scoping review is to describe the nature of empirical research on a given topic. As this reviewer noted, grey literature largely offers instruments, data sets, and various types of reports that may not be empirical research; therefore, to optimize yield, we searched the standard indexed research databases only; moreover, research conducted by professional organizations that is of a rigorous nature is generally published in the peer-reviewed literature and would have been identified by our search of indexed databases
- Grey literature has been described by others (who we now cite, see below) as time-consuming with low yield, there are no gold standards for systematic grey literature searching methods plus evaluations found in grey literature and information may be at high risk of bias for a number of reasons; hence, it is not a mandatory requirement of systematic reviews
- Grey literature searching also includes contacting key informants for referrals to relevant information further adding to the time-consuming nature – it has been compared to primary research. Thus, it is highly dependent on the availability of resources.

We had no funding for this research and relied on two students to help us complete this work. Given the low yield and limited resources, grey literature searching was not feasible.

In the original manuscript we explicitly acknowledged the lack of grey literature searching as a limitation. But, to elaborate on this issue, we did the following to provide more explanation for this decision:

- Methods, Eligibility criteria (page 5): “Eligible study designs included...qualitative...or quantitative...or mixed methods studies published in peer-reviewed journals.”
- Methods, Searching (page 6): “We did not search grey literature because it is time-consuming and costly with low yield, and not feasible given that we had few resources for this study; there are no standard methods for doing so, and grey information may be at high risk of bias.[18,19]”
- Discussion, Limitations (page 11): “We did not search the grey literature given the methodological challenges that have been identified by others.[18,19]”

#### VERSION 2 – REVIEW

<b>REVIEWER</b>	Carla Saunders University of Technology Sydney
<b>REVIEW RETURNED</b>	24-Nov-2017

<b>GENERAL COMMENTS</b>	For openness and transparency please ensure that an acknowledgement is made to the fact that by not including the professional grey literature in this review, important information on this topic area may have been missed.
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<b>REVIEWER</b>	Taya Irizarry University of Pittsburgh USA
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<b>REVIEW RETURNED</b>	28-Nov-2017
<b>GENERAL COMMENTS</b>	I believe the authors have done an excellent job addressing all of the comments from the reviewers. I believe it ready for publication.
<b>REVIEWER</b>	Mariona Pons-Vigués IDIAP Jordi Gol, Barcelona, Catalonia
<b>REVIEW RETURNED</b>	15-Nov-2017
<b>GENERAL COMMENTS</b>	The methods used are adequate for the study objective. The authors describe with detail the methods and the interpretation and discussion of results are appropriate. The manuscript is well written. Most comments have been addressed sufficiently. In my opinion, no changes are needed.

### VERSION 2 – AUTHOR RESPONSE

We are thrilled that BMJ Open has provisionally accepted our manuscript pending minor edits. Many thanks for the opportunity to respond to remaining comments from three reviewers that are meant to further strengthen the manuscript. Reviewer #2 said that the manuscript is "ready for publication" and Reviewer #4 said that "no further changes are needed". The only comment to address is from Reviewer #1 (Carla Saunders): "For openness and transparency please ensure that an acknowledgement is made to the fact that by not including the professional grey literature in this review, important information on this topic area may have been missed."

In the last version submitted, in which we responded to similar concerns from previous Reviewers, we addressed Reviewer #1's concern as follows. We openly declared that we did not search the grey literature, offered a rationale for why we did not do so, and noted the lack of grey literature searching as a limitation.

#### Strengths and Limitations (page 3)

"All relevant studies may not have been identified or included because the search strategy may not have been sufficiently comprehensive, grey literature was not explored, non-English studies were excluded, and the screening criteria may have been overly stringent"

#### Methods, Searching (page 6)

We did not search grey literature because it is time-consuming and costly with low yield, and not feasible given that we had few resources for this study; there are no standard methods for doing so, and grey information may be at high risk of bias.[18,19]

#### Methods, limitations paragraph (page 11-12)

Several issues may limit the interpretation and application of the findings. Despite having conducted a comprehensive search of multiple databases that complied with standards for search strategies,[17] it was limited to English language studies. We did not search the grey literature, assuming that empirical research would be identified in indexed databases given the methodological challenges that have been identified by others.[18,19] The search strategy may not have identified all relevant studies or our screening criteria may have been too stringent. Few studies were eligible and those studies provided few specific details about what patients were meant to do or actually did. Risk of bias of included studies was not assessed as this is not customary for a scoping review. Although scoping

reviews often include consultation with stakeholders to interpret the findings,[15] this step was not done because studies were few and provided sparse details.

In a new version, to further address Reviewer #1's concern, we edited the limitations paragraph in the Discussion (page 11-12) from "We did not search the grey literature, assuming that empirical research would be identified in indexed databases given the methodological challenges that have been identified by others.[18,19]" to "We did not search the grey literature, assuming that empirical research would be identified in indexed databases given the methodological challenges that have been identified by others; as a result, important information may have been missed.[18,19]"