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## Patient engagement in hospital health service planning and improvement: a scoping review

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# Patient engagement in hospital health service planning and improvement: a scoping review

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## ABSTRACT

### Objectives

Patient engagement (PE) improves patient, organization and health system outcomes but faces numerous challenges. Most PE research was based on primary care. The purpose of this research was to characterize primary research on PE in hospitals.

### Design

Scoping review

### Methods

MEDLINE, EMBASE, CINAHL, HealthStar and the Cochrane Library were searched from 2006 to September 2016. English language studies that evaluated patient or provider beliefs or participation in PE, or PE influencing factors or impact were eligible. Screening and data extraction were done in triplicate. PE characteristics, influencing factors and impact were extracted and summarized.

### Results

Of 3,939 published reports identified, 3,914 were unique, and 3,690 were excluded. Of 276 full-text articles screened, 10 were included. None evaluated behavioural interventions to promote or support PE. While most studies examined involvement in standing committees or projects, patient input and influence on decisions was minimal. Lack of skill and negative beliefs among providers were PE barriers. PE facilitators included careful selection and joint training of patients and providers, formalizing patient roles, informal interaction to build trust, involving patients early in projects, small team size, frequent meetings, active solicitation of patient input in meetings and debriefing after meetings. Asking patients to provide insight on problems rather than solutions, and provider champions may enhance patient influence on hospital services.

### Conclusions

Given the important role of PE in improving hospital services and the paucity of research on this topic, future research should develop and evaluate behavioural interventions for PE directed at patients and providers informed by the PE barriers and facilitators identified here, and should assess the impact on various individual and organizational outcomes.

### Systematic Review Registration

None

### Keywords

hospital care, quality improvement, patient-centred care, patient engagement, implementation science, scoping review

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**STRENGTHS and LIMITATIONS**

- This study addressed a gap in knowledge about the characteristics of research on how to engage patients in hospital service planning and improvement
- This study used rigorous scoping review methods including a detailed search of multiple databases that complied with standards for search strategies, employed a framework of patient and family engagement to characterize patient engagement activities, and complied with standards for the conduct and reporting of reviews
- 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
- Few studies were eligible and those studies provided few specific details about what patients were meant to do or actually did, thus little knowledge was revealed about how to optimize patient engagement in hospital service planning and improvement
- Although scoping reviews often include consultation with stakeholders to interpret the findings, this step was not done because studies were few and provided sparse details.

## BACKGROUND

Patient engagement (PE) in health care is 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] Research has largely focused on engaging patients in securing their own appropriate, effective, safe and responsive health care, also referred to as patient-centred care.[3,4] Previous syntheses of research on PE in their own care generated insight on approaches or technologies to support PE.[5,6] Examples include providing care in a compassionate and empowering manner by sharing information and being sensitive to patient needs,[7] interprofessional collaboration and case management to optimize the coordination of care, and prompting patients to enhance the safety of their own care by reminding health care professionals to use practices such as hand hygiene or the surgical safety checklist.[8]

Patients can also be engaged in designing or improving health services through activities such as completing surveys about their care experiences, or serving as advisors or members of governance or quality improvement committees.[9] Strategies that have been found to support PE in service improvement include joint training of patients and frontline health care professionals, clearly defined roles and responsibilities, and trained facilitators to coach teams.[10] However, such ideal environments may not be the norm. A systematic review of 26 studies published from 2000 to 2015 found that barriers of PE in health service improvement were lack of training and uncertainty about role among patients, and health care professional uncertainty about how to work with patients and act on their feedback, resulting in token PE.[11] Similarly, a qualitative systematic review of 11 studies published from 2003 to 2012 found that PE in service improvement was challenged by inadequate planning and differing patient and health care professional views, and that PE was token in most circumstances and did not lead to improvements.[12] Therefore, information is needed on the effective strategies and optimal conditions for PE in service improvement. Such knowledge could provide insight on how to support widespread implementation of PE and greater translation of the patient voice to improved services.

Research on PE in service improvement has thus far largely focused on the primary care setting.[10-12] A considerable proportion of health care is delivered in hospitals, which also seek to optimize service delivery and associated outcomes through PE.[13] Hospital care differs from primary care in setting, conditions/diseases, procedures and providers therefore PE activities, supportive conditions and outcomes may also differ. The quantity and nature of research on PE in hospital-based service improvement has not been previously characterized. 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.

## METHODS

### Approach

This review sought to describe research on the variety of ways in which patients have been engaged in hospital health service improvement. Therefore, rather than a traditional systematic review that seeks to describe outcomes, a scoping review was conducted.[14,15] This approach was employed to acquire an understanding of the extent, range and nature of research on this

topic, describe PE and its determinants and impact, and identify issues that warrant further research. A scoping review involves five steps: scoping, searching, screening, data extraction and data analysis. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses criteria guided the conduct and reporting of this review.[16] Data were publicly available so institutional review board approval was not necessary. A protocol for this review was not registered.

**Scoping**

The scoping step involved becoming familiar with the literature on this topic. A preliminary search was conducted in MEDLINE using Medical Subject Headings including, but not limited to (consumer participation or patient participation) and (program evaluation or quality improvement or hospital administration or hospital planning or health services research). ARG and two trainees (LL, AC) screened titles and abstracts of the search results, which informed the ultimate search strategy and were used to generate eligibility criteria based on the PICO (Population, Intervention, Comparisons, Outcomes) framework. All members of the research team reviewed eligibility criteria and provided feedback, which was used to refine the eligibility criteria. The research team included a physician with expertise in geriatric medicine (SES), health services researchers with expertise in patient safety, quality improvement and PE (WW, RB, SES, RU, ARG) and experts in evidence syntheses (ARG, RU, SES).

**Eligibility criteria**

*Population* referred to both patients and providers. Patients included adults (aged 18+ years) who visited hospitals in any ambulatory, emergent, or inpatient capacity for any health care issue, condition, or disease; or were family members, care givers or well members of the public (all henceforth referred to as patients). Providers included any type of clinicians, executives or managers working in hospitals of any type. *Interventions* 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.[9] Interventions also included strategies directed at either patients or providers to promote or support PE in service improvement. With respect to *comparisons*, studies were eligible if they explored ways that patients (or family members/caregivers/public) or providers were involved in PE; their views, experiences of, and suggestions to support PE; or evaluated whether and how PE-informed improvements were implemented, strategies used to support PE, or the impact of PE on health services or patient outcomes. Such studies may have included patients or providers with and without exposure to interventions, or before or after exposure to interventions, or receiving different types of interventions. *Outcomes* were any reported by eligible studies and included, but were not limited to, awareness, knowledge, communication, experiences or impact of PE, types of PE activities, factors influencing any of these functions, the impact of behavioural interventions to support PE, or the impact of PE. Eligible study designs included English language qualitative (interviews, focus groups, qualitative case studies), quantitative (questionnaires, randomized controlled trials, time series, before/after studies, prospective or retrospective cohort studies, case control studies, economic analyses) or mixed methods studies.

Studies were not eligible if they involved individuals under the age of 18, providers not based in hospitals, or more than half were trainees such as interns, residents or fellows; or assessed PE in their own care or PE in health service improvement not based in hospitals. The following



publication types were not eligible: systematic reviews, protocols, editorials, commentaries, letters, news items, or meeting abstracts or proceedings. If more than one publication described a single study and reported different data, they were all included but counted as a single study; if they reported the same data only the most recent publication was included.

## Searching

The search strategy (Supplementary File 1) was developed by ARG (trained as a medical librarian) in conjunction with a professional medical librarian and complied with the Peer Review of Electronic Search Strategy reporting guidelines.[17] MEDLINE, EMBASE, CINAHL, HealthStar and the Cochrane Library were searched on September 20, 2016 for articles published from 2006 to 2016. The year 2006 was chosen to capture the most recent ten years of research given that PE is a relatively new phenomenon. Systematic reviews were not eligible but their references and those of all eligible studies were screened to identify additional eligible primary studies.

## Screening

To prepare for screening of titles and abstracts, ARG, LL and AC independently screened titles and abstracts of the first 25 search results, then discussed discrepancies, and how to interpret and apply the eligibility criteria. LL and AC independently screened titles and abstracts according to specified PICO-based eligibility criteria. All items selected by at least one reviewer were retrieved. Full text articles were independently screened by LL and AC prior to data extraction; they consulted ARG weekly to resolve uncertainty in inclusion decisions.

## Data extraction

A data extraction form was developed to collect information on author, publication year, country, research design, number and type of participants, description of PE and/or other intervention, and findings. LL, AC and ARG independently pilot-tested data extraction on three articles and compared findings by discussion to refine the data extraction form. AC and LL independently extracted data from eligible articles; all extracted data were independently checked by ARG.

## Data analysis

Summary statistics were used to describe the number and/or proportion of studies by year published, country, research design, and those that assessed type and extent of PE, factors influencing PE, and PE interventions and impact. The type and extent of PE were categorized independently during data extraction using the Carman et al. framework of patient and family engagement that characterizes PE by level of engagement (own care, organizational design and governance, policy making) and continuum of engagement (consultation, involvement, partnership and shared leadership).[9] For this study, which focused on PE for the organizational design and governance of hospitals, types of PE were organized according to activities that consulted, involved or partnered with patients. The quality of individual studies was not assessed because that is not customary for a scoping review. All co-authors reviewed the summary of findings and their feedback was incorporated in the final version.



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# RESULTS

## Search results

A total of 3,939 studies were identified by searches, of which 3,914 were unique items. Screening of titles and abstracts excluded 3,634 as irrelevant to PE in hospital service improvement and 56 because they were systematic reviews that were relevant to PE in hospital service improvement. Screening of primary studies in the references of those systematic reviews identified another 3 potentially eligible articles. Among 276 full-text primary studies that were screened, 214 were excluded because the study was not hospital-based (90), the publication type was not eligible (68), the study was not based on PE (36), PE focused on individual care (13), participants were under 18 years of age (5), methodologic details were lacking (1) and 1 was a duplicate study. Ten studies were included in the review (Figure 1). Data extracted from included studies is summarized in Supplementary File 2.[18-27]

## Study characteristics

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] One study was published in each of 2008 and 2009, and 2 studies per year were published in each of 2010, 2011, 2013 and 2014. Four studies were conducted in the United Kingdom (25.0%), 2 in Australia (16.7%) and 1 (8.3%) in each of Canada, Norway, Taiwan and Uganda. With respect to research design, 4 studies were qualitative case studies most frequently involving interviews and observation, 3 employed qualitative interviews and/or focus groups, and 3 were cross-sectional surveys.[3] Two studies collected data from patients, 3 studies from providers, and 5 studies from both patients and providers.

## Type of PE

All 10 studies identified types of activities in which patients were engaged and their roles in those activities. Little detail was provided about precisely what patients were meant to do or did in relation to these activities. Patients were standing members of quality committees,[18] hospital management committees,[19,26] or advisory panels, councils or networks.[19,20,21,23,27] They were also members of shorter-term project teams.[18,20,22,23,25] In 3 studies, patients provided solicited feedback by one-time questionnaire or interview about how to improve services.[20,24] In 1 study, patients voluntarily provided feedback about services by mass media or suggestion boxes.[26] In 1 study, patients provided education to other patients.[23] Patients assumed several roles in those activities: developing quality criteria,[18] reviewing quality improvement project results,[18,27] identifying issues that warranted improvement,[19,20,24,26] suggesting potential solutions for addressing problems,[23] and informing the design or reorganization of services.[18,21,22,25]

Types of PE activities were characterized by continuum of engagement (Table 1). Three studies (30.0%) focused on consultation activities: questionnaire, interview, mass media and suggestion boxes.[20,24,26] Eight studies (80.0%) focused on involvement activities: members of standing committees, advisory bodies, project teams or providing education to other patients.[18-23,25,27] One study focused on a partnership where citizen advisory panel recommendations on core services were adopted by a hospital board for a restructuring initiative.[21]

Table 1. Type of PE activities

Consultation	Involvement	Partnership and shared leadership
<ul style="list-style-type: none"> <li>• Provide solicited feedback questionnaire or interview on how to improve services[20,24]</li> <li>• Provide voluntary feedback through mass media or suggestion boxes[26]</li> </ul>	<ul style="list-style-type: none"> <li>• Members of quality committees[18]</li> <li>• Members of hospital management committees[19,26]</li> <li>• Members of advisory panels, councils or networks[19,20,21,23,27]</li> <li>• Members of project teams[18,20,22,23,25]</li> <li>• Provide education to other patients[23]</li> </ul>	<p>Members of a citizen advisory panel that prioritized core services to inform hospital restricting; recommendations were largely adopted by the hospital board[21]</p>

### Extent of PE

Five (50.0%) studies described the extent to which patients were engaged as members of standing committees or project teams. A survey of providers at 74 European hospitals found that patients were infrequently involved in activities such as developing quality criteria or designing or reorganizing services (range 50.0% to 64.8%) and this did not differ across clinical departments.[18] Observation of 10 hospital committee meetings and 11 community network meetings in 8 regions revealed that patient input was minimal; even when they contributed, their influence on decisions was minimal, and their ideas were not pursued by providers subsequent to meetings.[19] 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.[22] A survey of 142 providers who had been on committees with patients revealed that patients did not often fulfill the roles of sharing their experiences, asking difficult questions or improving communication between the health service and the community.[25] Interviews with providers, and focus groups with patients and providers revealed that patients did not perceive themselves to be partners in improving service delivery, and hospital management committees or providers did not use patient feedback.[26]

### Factors influencing PE

Seven studies (70.0%) assessed facilitators or barriers to PE (Table 2). Barriers included lack of knowledge among providers on how to engage with an empowered group of questioning patients,[27] lack of guidance on the role of patients and how they should be involved,[22,25] beliefs of providers who questioned the relevance and representativeness of individual patient experiences,[19,26] or their capacity to contribute given lack of criteria for inclusion or a vetting process,[22] the beliefs of providers that patient feedback was complaining and patients were hostile and ungrateful,[26,27] infrequent meetings,[22] disagreement between patients and providers on the role of patients,[25] lack of informal opportunities outside of meetings for interaction to build trust,[22] dysfunction and hierarchies among providers,[22] and pressure on

providers from senior management to achieve specific objectives that diverged from patient objectives.[27]

Facilitators included selection of patients based on their personal characteristics and skills,[22] early involvement in projects so that patients were familiar with objectives and could offer meaningful contributions to shape the project’s aims and activities,[20] meeting monthly or more frequently if needed,[22] small team size that was less hierarchical and more easily integrated patients,[22] involving patients and staff with the desire to work together,[22] explicit effort to involve patients in meetings and extend value and respect for their input,[20,22,27] debriefing with patients after meetings to gather feedback about how the session had gone and how interaction could be improved,[20] formal interaction supplemented with informal interaction by email or telephone to build relationships,[20] and formalizing patient roles by labelling and recognizing their position.[20,22] One study that used narrative interviewing as an approach to collect input from patients on how to improve health care services found that asking about feelings helped patients to express themselves more freely and provide detailed accounts of their experiences.[24]

Table 2. Factors influencing PE

Facilitators	Barriers
<ul style="list-style-type: none"><li>• Selection of patients based on their personal characteristics and skills[22]</li><li>• Involving patients and staff with the desire to work together[22]</li><li>• Involving supportive staff with leverage to navigate hospital processes to effect change[19]</li><li>• Early involvement in projects so that patients were familiar with objectives and could offer meaningful contributions to shape the project’s aims and activities[20]</li><li>• Meeting monthly or more frequently if needed[22]</li><li>• Small team size that was less hierarchical and more easily integrated patients[22]</li><li>• Explicit effort to involve patients in meetings and extend value and respect for their input[20,22,27]</li><li>• Debriefing with patients after meetings to gather feedback about how the session had gone and how interaction could be improved[20]</li><li>• Formal interaction supplemented with informal interaction by email, telephone or other interaction to build relationships[20]</li><li>• Formalizing patient roles by labelling and recognizing their position[20,22]</li></ul>	<ul style="list-style-type: none"><li>• Lack of knowledge among health care professionals on how to engage with an empowered group of questioning patients[27]</li><li>• Lack of guidance on the role of patients and how they should be involved[22,25]</li><li>• Health care professional beliefs about the relevance and representativeness of individual patient experiences[19,26]</li><li>• Health care professional beliefs about patient capacity to contribute given lack of criteria for inclusion or a vetting process[22]</li><li>• Health care professional beliefs that patient feedback was complaining and patients were hostile and ungrateful[26,27]</li><li>• Infrequent meetings[22]</li><li>• Disagreement between patients and health care professionals on the role of patients[25]</li><li>• Lack of informal opportunities outside of meetings for interaction to build trust[22]</li><li>• Dysfunction and hierarchies among the health care professionals[22]</li><li>• Pressure from senior management to achieve specific objectives that diverged from patient objectives[27]</li></ul>

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| <ul style="list-style-type: none"> <li>• Asking patients about feelings to prompt detailed accounts of their experiences[24]</li> <li>• Joint training of patients and health care professionals[20]</li> <li>• Patient recommendations that align with what health care professionals consider appropriate[23]</li> </ul> |  |
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Three studies (30.0%) explored the mechanism by which patients influenced the beliefs or actions of providers with whom they interacted. Patient influence appeared to occur through participation in training and meetings with providers,[20] and outside of formal meetings during opportunistic interaction between patients and providers who were supportive and navigated hospital processes to effect change.[19] Patient influence was greater when it provided unique insight on problems that allowed providers to identify new possibilities for solutions compared with patients recommending solutions, and was viewed as particularly valuable when it aligned with what providers viewed as appropriate.[23]

### PE interventions

No studies developed or evaluated behavioural interventions that would promote or support PE by influencing patient or provider beliefs or actions.

### PE impact

No studies assessed the impact of PE on clinical outcomes. A single study evaluated the impact of PE on participants and health services. Observation of 5 full-day meetings of a 28-member citizen panel convened to establish hospital restructuring priorities and survey of participants after each meeting found they were enthusiastic about the experience, and thought sessions were well organized and the facilitators effective, although some patients were anxious about the magnitude and complexity of the task.[21] Participants thought the panel had accomplished something important that benefited the community and the hospital, and the citizen panel was an effective way to incorporate the community's perspective in decision making. The hospital board approved nearly all panel recommendations resulting in the closure of 26 beds, two outpatient programs, integration of a program with the emergency department, and a transition strategy; changes resulted in a balanced budget in both the 2010-11 and 2011-12 fiscal years.

## DISCUSSION

This scoping review identified few studies published since 2006 that evaluated PE based on consultation, involvement or partnership for hospital service improvement; no studies evaluated interventions that would promote or support PE by influencing patient or provider beliefs or actions. Most studies examined patient involvement in standing committees or projects but few details were provided about those activities. Patient input and influence on decisions was minimal. Only one study evaluated how PE impacted hospital services and no studies evaluated the impact of PE on clinical outcomes. Barriers to PE were primarily at the provider level including negative beliefs and attitudes about patient roles and input, lack of knowledge and skills, provider dysfunction and hierarchies, and uncertainty about how to resolve differences between patient and senior management priorities. Facilitators of PE included joint training of patients and providers, formalizing patient roles, informal interaction to build trust, involving

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3 them from the outset of projects, small team size, frequent meetings, active solicitation of patient  
4 input during meetings and debriefing after meetings.  
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7 The strengths of this study include use of rigorous scoping review methods,[14,15] compliance  
8 with standards for the conduct and reporting of reviews,[16] and use of a framework of patient  
9 and family engagement to characterize PE activities.[9] Several issues may limit the  
10 interpretation and application of the findings. Despite having conducted a comprehensive search  
11 of multiple databases that complied with standards for search strategies,[17] it was limited to  
12 English language studies. We did not search the grey literature, assuming that empirical research  
13 would be identified in indexed databases. The search strategy may not have identified all  
14 relevant studies or our screening criteria may have been too stringent. Few studies were eligible  
15 and those studies provided few specific details about what patients were meant to do or actually  
16 did. Risk of bias of included studies was not assessed as this is not customary for a scoping  
17 review. Although scoping reviews often include consultation with stakeholders to interpret the  
18 findings,[15] this step was not done because studies were few and provided sparse details.  
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22 The findings of this study concur with previous research based in primary care, which revealed  
23 that PE was token in nature, thus patients did not inform service design or improvement.[10-12]  
24 Barriers (provider beliefs and skills) and facilitators (clearly defined roles for patients, joint  
25 training of patients and providers) of PE in the primary care setting also emerged in this  
26 study.[10-12] However, this study identified additional barriers and facilitators that may be  
27 unique to the hospital context. Identifying barriers and facilitators is an important first step in the  
28 selection and tailoring of behavioural interventions for patients and providers that could be  
29 implemented to promote and support PE.[28] Having identified barriers and facilitators is  
30 particularly important given the paucity of included studies that evaluated behavioural  
31 interventions for PE.  
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35 This review identified two mechanisms underlying the success of PE, both of which may  
36 mitigate the lack of skills and negative beliefs among providers that were consistent barriers to  
37 PE. These mechanisms should be considered when designing PE activities. One included study  
38 found that patient influence on hospital services was more likely when providers were supportive  
39 and navigated hospital processes to effect change.[19] It may be crucial to carefully select and/or  
40 train providers that participate in committees or project teams with patients so that they function  
41 as champions. It is well-recognized that champions can improve service delivery and clinical  
42 outcomes,[29] by influencing the knowledge and behavior of their colleagues.[30] Another  
43 included study found that patient influence on hospital services was more likely when patients  
44 were asked to provide unique insight on problems that allowed providers to identify new  
45 possibilities for solutions rather than for patients to recommend solutions that were not viewed  
46 by providers as relevant or appropriate.[23] This approach could be accommodated in PE  
47 activities that consulted, involved or partnered with patients, appears to a comfortable role that  
48 allows patients to express themselves freely and provide detailed accounts of their  
49 experiences,[24] and would ensure that providers were engaged rather than alienated by the  
50 process.  
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54 The value of a scoping review is to reveal issues for which knowledge is lacking that warrant  
55 future research. This study identified several such issues. Few types of PE activities were  
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examined in included studies. Therefore, ongoing primary research should develop and evaluate the same and additional types of PE activities. Those activities should address the continuum of PE including consultation, involvement and partnership since all three categories of PE activities may be appropriate for different health service improvement objectives. This review found that patient input and influence on decisions was minimal. 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,[31] or the Effective Practice and Organisation of Care taxonomy,[32] and formal processes for developing behavioural interventions such as Intervention Mapping.[33] One study only examined the impact of PE on participants and health services; no studies assessed the impact of PE on clinical outcomes. Ongoing research that tests the effectiveness of PE behavioural interventions should assess the impact on various individual and organizational outcomes.

## CONCLUSION

Few studies have evaluated hospital PE to identify the best activities, roles and behavioural interventions for patients and providers that support PE and result in improved health services and patient outcomes. Lack of skill and negative beliefs among providers was a consistent barrier to PE. This review identified numerous facilitators and mechanisms that could be employed by hospitals to optimize PE and its impact. Further research is needed to elaborate on PE activities suitable for consultation, involvement and partnership; test behavioural interventions for PE directed at patients and providers informed by the PE barriers and facilitators identified here; and demonstrate the impact of PE. This would identify types of PE activities and supportive conditions that should be prioritized by hospitals.

## COMPETING INTERESTS

The authors have no conflicts to declare

## CONTRIBUTORS

ARG envisioned and planned the study, and provided funding for research assistant support. All authors established study objectives, collected and analyzed or interpreted data, drafted or edited the manuscript, and read and approved the final manuscript.

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## DATA SHARING

All data are available in the manuscript or supplementary files

## ETHICS

All data were publicly available therefore ethics review and approval were not required

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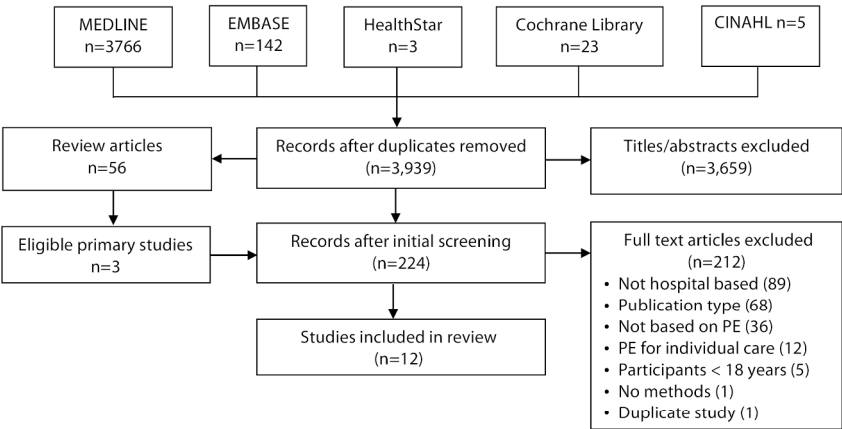


Figure 1. PRISMA diagram

215x132mm (300 x 300 DPI)

## Additional File 1. Search strategy

1 decision making, organizational/ (8026)  
 2 Hospital Planning/mt, og [Methods, Organization & Administration] (408)  
 3 Organizational Objectives/ (14564)  
 4 "organization and administration"/ (2122)  
 5 Patient Care Management/mt, og [Methods, Organization & Administration] (1282)  
 6 Health Services Administration/og [Organization & Administration] (58)  
 7 committee membership/ (556)  
 8 governing board/ (2770)  
 9 institutional management teams/ (1322)  
 10 planning techniques/ (6475)  
 11 organizational innovation/ (17755)  
 12 hospital administration/ (6663)  
 13 Health facility administration/ (1069)  
 14 Professional staff committees/ (1340)  
 15 Health Services Research/mt, og [Methods, Organization & Administration] (5493)  
 16 Program Evaluation/ (44928)  
 17 Quality Assurance, Health Care/mt, og [Methods, Organization & Administration] (10605)  
 18 Quality Improvement/og [Organization & Administration] (2072)  
 19 "Quality of Health Care"/og [Organization & Administration] (3110)  
 20 research/ or behavioral research/ or operations research/ or research design/ (106452)  
 21 Patient-Centered Care/mt, og [Methods, Organization & Administration] (5523)  
 22 Consumer Participation/ (9801)  
 23 Patient Participation/ (15899)  
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 41 (user adj2 participat\*).tw,kw,ti,ab. (167)  
 42 or/1-20 (216918)  
 43 or/21-41 (74443)  
 44 42 and 43 (7674)  
 45 limit 44 to (english language and yr="2006 -Current") (4434)  
 46 limit 45 to (case reports or clinical study or clinical trial, all or clinical trial, phase i or clinical trial, phase ii or clinical trial, phase iii or clinical trial, phase iv or clinical trial or comparative study or controlled clinical trial or pragmatic clinical trial or randomized controlled trial) (668)  
 47 limit 46 to (comment or editorial or interview or lectures or letter or news) (1)  
 48 46 or 47 (668)  
 49 45 not 48 (3766)

Additional File 1. Data extracted from included studies

Author Year Country	Objective	Research design	Results
Groene 2014 UK	To describe the involvement of patients in quality management functions	Survey of 72 hospital quality managers and 16 heads of clinical units for clinical pathways for myocardial infarction, stroke, hip fracture, and deliveries in 7 countries: Czech Republic, France, Germany, Poland, Portugal, Spain and Turkey	Most respondents said that patients were never involved in various quality management functions; this did not differ across clinical pathways: <ul style="list-style-type: none"><li>• developing quality criteria (56.7%; p=0.211)</li><li>• designing/organizing processes of care (60.8%; p=0.217)</li><li>• quality committees (64.8%; p=0.276)</li><li>• quality improvement projects (50.0%; p=0.202)</li><li>• discussion of quality improvement project results (59.4%; p=0.322)</li></ul>
Nathan 2014 Australia	To explore how community members influenced over hospital health service planning and improvement	Qualitative case study involving interviews with 10 community members and 24 hospital managers and observation of meetings of hospital committees (n=10), community member networks (n=11) and the community member council (n=5) from 8 areas	<ul style="list-style-type: none"><li>• Community members said they were deeply committed to making a difference for patients</li><li>• During committee meetings controlled by hospital staff their input was minimal; even when they did contribute to discussions, their influence on decisions was minimal</li><li>• In network meetings that were community-controlled community members raised numerous issues for action; hospital representatives attending these meetings appeared open to the ideas but the ideas were not pursued subsequent to meetings</li><li>• During interviews, staff questioned the representativeness of community members and the relevance of their personal experiences; however, they also identified the value and specific impact of community members on hospital services</li><li>• Community member influence occurred outside of formal meetings during opportunistic interaction with supportive staff who navigated hospital processes to effect change</li></ul>
Armstrong 2013 UK	To describe patient involvement in quality improvement	Qualitative case study of three projects involving qualitative interviews with 126 patients and providers and observation of meetings across three projects (two based in hospitals, one in primary care)	<ul style="list-style-type: none"><li>• Rationale for involving patients varied: externally mandated, perceived value of patient involvement based previous work, lack of any previously collected data on the patient experience, belief among providers that capturing the patient experience was important</li><li>• Patients were engaged through a virtual network of patients who could be consulted as required, questionnaires, patient representative on the project team throughout the course of the project, participation in regional meetings, and advisory groups that worked with project teams</li><li>• Facilitators of meaningful involvement were early involvement so that patients could understand the project's aims and shape the work, debriefing after meetings to provide feedback on how the session had gone, less formal interaction through email and phone calls, explicit value and respect for input from all team members, and formalizing patient roles</li><li>• Patients exerted influence by persuading clinicians that there was an important problem to be addressed and about how it should be addressed; this was largely achieved by participation in meetings and training events with clinicians; and by acting as knowledge brokers to build links between patients and clinicians</li></ul>

Chan 2013 Canada	To outline how an Ontario hospital initiated an intensive Citizens' Advisory Panel related to budget and service provision decisions	Qualitative case study (surveys and direct observation)	<ul style="list-style-type: none"> <li>After each CAP session, members were surveyed. Members were enthusiastic about participating, generally thought the sessions were well organized, and agreed the facilitators were effective.</li> <li>There was frustration with the public roundtable in terms of its limited attendance, and the event's representativeness and overall merit.</li> <li>CAP members were also surveyed prior to the board presentation (14 responses, 56% response rate). Although enthusiasm about participation in the panel remained strong, there was also some anxiety because of the magnitude and complexity of the recommendations.</li> <li>A final questionnaire mailed to CAP members after announcements of hospital service changes (12 responses, 48% response rate) found that members generally had a positive view of their experience, thought the panel had accomplished something important, and had been of benefit to the community and the hospital.</li> <li>Overall, 75% of the respondents thought the CAP was an effective way to incorporate the community's perspective in decision making.</li> <li>Some individuals in the public expressed anger about service cuts, although none of the anger was directed at the process or panel members.</li> </ul>
Martin 2011 UK	To explore how patients were involved in working with health care professionals to design and improve patient-centred cancer genetic services	Qualitative case study including interviews with 32 staff (physicians, nurses, genetic counsellors, managers) from cancer-genetics services and 12 patients, and observation of 21 meetings across 5 sites	<ul style="list-style-type: none"> <li>At 4 sites, 1 or 2 patients were invited to planning meetings.</li> <li>Observation found that patients attended but were largely silent.</li> <li>Interviews found that patients felt they were not effectively involved as partners and their suggestions were ignored; staff at these sites agreed.</li> <li>Barriers included lack of guidance on the role of patients, how they should be involved; staff suspicion about the capacity of patients to contribute given lack of criteria for inclusion or a vetting process; infrequent meetings; lack of informal opportunities outside of meetings for interaction to build trust; dysfunction and hierarchies among the health care professionals.</li> <li>At 1 site patients and health care professionals viewed the work as a genuine partnership.</li> <li>Facilitators included selection of patients based on their personal characteristics and skills; the team met monthly and sometimes more frequently if needed; small team size that was less hierarchical and more easily integrated patients; patients and staff were keen to form close, informal bonds that would support their working together; and conscious effort to involve patients in meetings; patients were granted 'volunteer status' by the hospital, which formalized their roles.</li> </ul>
Solbjør 2011 Norway	To explore clinician views about the value and involvement of patients in health service improvement	Qualitative interviews with 18 physicians, nurses, other health care professionals and health care managers from 12 regions	<ul style="list-style-type: none"> <li>Patients were involved in user committees that regularly met with management, project groups that worked for limited periods of time, as representatives of regional councils and by providing education to other patients.</li> <li>User involvement was viewed as valuable when it provided unique insight on problems that created new possibilities for solutions, and particularly valuable when it aligned with what they viewed as appropriate.</li> </ul>

Hsu 2010 Taiwan	To evaluate a narrative interviewing approach (story-telling) to collect information from older people about how to improve health care services	Qualitative interviews with 20 patients aged 65 or older in a rehabilitation unit at a single hospital	<ul style="list-style-type: none"><li>• The study found it unhelpful to use broad questions at the beginning to understand older people's unique meaning attached to health care service; supplementary probe questions offered limited help to understand the narrators' thoughts in relation to their hospital stay experiences</li><li>• Instead, warm-up questions such as "Tell me how you feel when you stay in the hospital?" could help patients express themselves freely and build rapport with the researcher. They found that it was only when narrators were asked about "feelings" that they provided a more detailed account of what they had experienced from their surroundings.</li><li>• Ward meetings and rounds were viewed as the best opportunity to identify and recruit patients compared with nursing notes, reviewing patient assessment records or during nurse handovers.</li><li>• The best time to conduct interviews was immediately after a patient had been notified of their discharge date</li><li>• The interviews revealed that nursing assessment skills such as listening and probing could be applied to interviewing older people</li></ul>
Nathan 2010 Australia	To examine health care professional views about the value and roles of community members on health service committees	Questionnaire survey of 142 clinicians and managers from one region that had been on a committee with community members	<ul style="list-style-type: none"><li>• 94% of staff had been on a committee with community representation; 26 % had been a chair and 19% had been a support person for community members</li><li>• The most common types of community member influence were strategic planning, priority setting, service redesign, service delivery, and improved signage and patient information</li><li>• 75% said that community members represented the views of the broader community</li><li>• 40% said that community members and health care professionals agreed on the role of community members, and 30% said that they understood the community member role and how to work with them</li><li>• Most agreed that community members' role was to improve communication between the health service and the community (98%), share their experiences (68%) and ask difficult questions (59%)</li><li>• Fewer agreed that community members actually fulfilled each of these roles</li></ul>
Longtin 2009 Switzerland	To explore patient views about patient participation in quality improvement by reminding health care professionals about hand hygiene	Questionnaire survey of 194 patients at a single teaching hospital	<ul style="list-style-type: none"><li>• 79% of respondents reported having heard about hospital acquired infections</li><li>• 68% of respondents considered infections a serious problem and more than 70% were worried about these infections</li><li>• Hand hygiene was correctly identified by 39% as the most important preventative measure</li><li>• 40% believed that patients should remind caregivers to cleanse their hands, and 29% thought that this would help prevent infections</li><li>• Most reported that they would not feel comfortable asking a nurse (76%) or a physician (77%) to cleanse their hands if they noticed they had not done so</li><li>• Respondents were less likely to intend to ask a physician than to ask a nurse to perform hand hygiene (29.9% vs 34%, p=0.04)</li><li>• However, an explicit invitation from a clinician significantly increased the intention to ask a physician (77.8%, p&lt;0.001) and to ask a nurse (82.5%, p&lt;0.001)</li><li>• The main reasons for not intending to ask clinicians about hand hygiene were the perception that caregivers already know (or should know) when to perform hand hygiene, the belief that asking about hand hygiene is not part of the patient's role, and a feeling of embarrassment or awkwardness</li></ul>



Rutebemberwa 2009 Uganda	To explore how hospitals acquired input from community members about hospital services	Qualitative interviews with 8 medical managers and 3 board members, and 8 focus groups with clinicians (n=NR) and 8 focus groups with community members (n=NR) from 8 hospitals in 5 districts	<ul style="list-style-type: none"> <li>Community members were involved in hospital management committees, or provided feedback through mass media like radio or suggestion boxes in hospitals</li> <li>Community members did not see themselves as partners in health care delivery, nor were they recognized as such</li> <li>Each hospital management committee had at least one community member recruited from religious groupings, political leaders or village opinion leaders; the majority of participants thought that these individuals were not representative of the community</li> <li>Hospital management committees did not use feedback from communities nor did communities receive any news from hospitals</li> <li>Community members used FM radio to phone in and share views about hospital services; clinicians and managers thought this was ineffective because the callers complaints were not substantiated and clinicians or managers did not have the opportunity to respond</li> <li>Managers said that feedback from suggestion boxes represented personal opinions and not those of the community; community members said suggestion boxes were not helpful because the very people they talked about were those who would review suggestion box feedback</li> <li>Some clinicians thought that the community was very happy with hospital services; other clinicians felt that the community grumbled but never conveyed their complaints to clinicians and some of those grumbling were ungrateful</li> </ul>
Brooks 2008 UK	To explore the role of patients in a nurse-led advisory council	Qualitative case study involving observation of 14 meetings and interviews with 18 nurses and 17 patients in a single hospital	<ul style="list-style-type: none"> <li>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</li> <li>Initially there were tensions between nurses and patients on committees</li> <li>Patients had clear ideas about how services could be developed based on their own or their families' experiences, and were frustrated when blocked from offering what they felt was a unique perspective and specialist knowledge</li> <li>Nurses felt they instead needed to address specific demands from senior management</li> <li>Nurses reacted negatively to what they viewed as patient 'storytelling' and 'subjective interruptions' that were irrelevant and hindered the smooth running of meetings</li> <li>Nurses were defensive and described patients as difficult, intimidating, ungrateful and hostile</li> <li>Nurses admitted to feeling inexperienced and unprepared to engage with an empowered questioning group of patients</li> <li>Over time conflict was resolved through ongoing discussions in meetings where patients were increasingly given a voice and nurses developed new ways of interacting with patients</li> </ul>

NR=not reported



PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	See title page
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	2-3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	3
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	3
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Additional File 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	4
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	4
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	4
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	n/a
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	4
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	4

## PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	n/a
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	4
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	5, Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, sex, age, COS, follow-up period) and provide the citations.	5-8, Additional File 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	n/a
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	5-8, Table 1, Table 2
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	n/a
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	5-8, Table 1, Table 2
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome and consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	8
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	9
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	9-10
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	10

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

# BMJ Open

## Patient engagement in hospital health service planning and improvement: a scoping review

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-018263.R1
Article Type:	Research
Date Submitted by the Author:	09-Nov-2017
Complete List of Authors:	Liang, Laurel; University Health Network Cako, Albina; University Health Network Urquhart, Robin; Beatrice Hunter Cancer Research Institute Dalhousie Straus, Sharon; St. Michael's Hospital, Li Ka Shing Knowledge Institute Wodchis, Walter; University of Toronto, Institute of Health Policy Management and Evaluation Baker, Ross; University of Toronto, IHPME Gagliardi, Anna; University Health Network, Toronto General Research Institute
<b>Primary Subject Heading</b>:	Patient-centred medicine
Secondary Subject Heading:	Health policy, Health services research
Keywords:	hospital care, quality improvement, patient engagement, scoping review

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# Patient engagement in hospital health service planning and improvement: a scoping review

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Word count 3,829

# ABSTRACT

## Objectives

Patient engagement improves patient, organization and health system outcomes but faces numerous challenges. Most patient engagement research is based on primary care. The primary purpose of this study was to describe the characteristics of published empirical research that evaluated PE in hospital health service improvement.

## Design

Scoping review

## Methods

Five databases were searched from 2006 to September 2016. English language studies that evaluated patient or provider beliefs or participation in patient engagement, or patient engagement influencing factors or impact were eligible. Screening and data extraction were done in triplicate. PE characteristics, influencing factors and impact were extracted and summarized.

## Results

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. None evaluated behavioural interventions to promote or support patient engagement. While most studies examined involvement in standing committees or projects, patient input and influence on decisions was minimal. Lack of skill and negative beliefs among providers were patient engagement barriers. Patient engagement facilitators included careful selection and joint training of patients and providers, formalizing patient roles, informal interaction to build trust, involving patients early in projects, small team size, frequent meetings, active solicitation of patient input in meetings and debriefing after meetings. Asking patients to provide insight on problems rather than solutions, and deploying provider champions may enhance patient influence on hospital services.

## Conclusions

Given the important role of patient engagement in improving hospital services and the paucity of research on this topic, future research should develop and evaluate behavioural interventions for patient engagement directed at patients and providers informed by the patient engagement barriers and facilitators identified here, and should assess the impact on various individual and organizational outcomes.

## Systematic Review Registration

None

## Keywords

hospital care, quality improvement, patient-centred care, patient engagement, implementation science, scoping review

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**STRENGTHS and LIMITATIONS**

- By describing the characteristics of published empirical research that evaluated patient engagement (PE) in hospital health service improvement, this research identified what is known about how to achieve PE in hospital health service improvement including facilitators and barriers
- This scoping review also exposed gaps in knowledge that inform future research in this area: develop and evaluate different types of PE along the continuum of consultation, involvement and partnership; develop behavioural interventions targeted at patients and providers to support PE, and evaluate the impact of PE on clinical outcomes
- This study used rigorous scoping review methods including a detailed search of multiple databases that complied with standards for search strategies, employed a framework of patient and family engagement to characterize patient engagement activities, and complied with standards for the conduct and reporting of reviews
- 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
- 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

## BACKGROUND

Patient engagement (PE) in health care is 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] Research has largely focused on engaging patients in securing their own appropriate, effective, safe and responsive health care, also referred to as patient-centred care.[3,4] Previous syntheses of research on PE in their own care generated insight on approaches or technologies to support PE.[5,6] Examples include providing care in a compassionate and empowering manner by sharing information and being sensitive to patient needs,[7] inter-professional collaboration and case management to optimize the coordination of care, and prompting patients to enhance the safety of their own care by reminding health care professionals to use practices such as hand hygiene or the surgical safety checklist.[8]

Patients can also be engaged in designing or improving health services through activities such as completing surveys about their care experiences, or serving as advisors or members of governance or quality improvement committees.[9] 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] However, such ideal environments may not be the norm. A systematic review of 26 studies published from 2000 to 2015 found that barriers of PE in health service improvement were lack of training and uncertainty about role among patients, and health care professional uncertainty about how to work with patients and act on their feedback, resulting in token PE.[11] Similarly, a qualitative systematic review of 11 studies published from 2003 to 2012 found that PE in service improvement was challenged by inadequate planning and differing patient and health care professional views, and that PE was token in most circumstances and did not lead to improvements.[12] Therefore, information is needed on the effective strategies and optimal conditions for PE in service improvement. Such knowledge could provide insight on how to support widespread implementation of PE and greater translation of the patient voice to improved services.

Research on PE in service improvement has thus far largely focused on the primary care setting.[10-12] A considerable proportion of health care is delivered in hospitals, which also seek to optimize service delivery and associated outcomes through PE.[13] Hospital care differs from primary care in setting, conditions/diseases, procedures and providers therefore PE activities, supportive conditions and outcomes may also differ. The quantity and nature of research on PE in hospital-based service improvement has not been previously characterized. The primary purpose of this study was to describe the characteristics of published 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 service improvement PE in the hospital context.

## METHODS

### Approach

Rather than a traditional systematic review that seeks to describe outcomes, a scoping review was conducted.[14,15] This approach was employed to acquire an understanding of the extent, range and nature of research on this topic, describe PE for hospital service improvement and its



determinants and impact, and identify issues that warrant further research. A scoping review involves five steps: scoping, searching, screening, data extraction and data analysis. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses criteria guided the conduct and reporting of this review.[16] Data were publicly available so institutional review board approval was not necessary. A protocol for this review was not registered.

**Scoping**

The scoping step involved becoming familiar with the literature on this topic. A preliminary search was conducted in MEDLINE using Medical Subject Headings including, but not limited to (consumer participation or patient participation) and (program evaluation or quality improvement or hospital administration or hospital planning or health services research). ARG and two trainees (LL, AC) screened titles and abstracts of the search results, which informed the ultimate search strategy and were used to generate eligibility criteria based on the PICO (Population, Intervention, Comparisons, Outcomes) framework. All members of the research team reviewed eligibility criteria and provided feedback, which was used to refine the eligibility criteria. The research team included a physician with expertise in geriatric medicine (SES), health services researchers with expertise in patient safety, quality improvement and PE (WW, RB, SES, RU, ARG) and experts in evidence syntheses (ARG, RU, SES).

**Eligibility criteria**

*Population* referred to both patients and providers. Patients included adults (aged 18+ years) who visited hospitals in any ambulatory, emergent, or inpatient capacity for any health care issue, condition, or disease; or were family members, care givers or well members of the public (all henceforth referred to as patients). Providers were included because research shows that PE is more likely when providers are trained for, and also engaged in PE.[10-12] Providers included any type of clinicians, executives or managers working in hospitals of any type. *Interventions* 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.[9] Interventions also included strategies directed at either patients or providers to promote or support PE in service improvement. With respect to *comparisons*, studies were eligible if they explored ways that patients (or family members/caregivers/public) or providers were involved in PE for hospital service improvement; their views, experiences of, and suggestions to support PE; or evaluated whether and how PE-informed improvements were implemented, strategies used to support PE, or the impact of PE on health services or patient outcomes. Such studies may have included patients or providers with and without exposure to interventions, or before or after exposure to interventions, or receiving different types of interventions. *Outcomes* were any reported by eligible studies and included, but were not limited to, awareness, knowledge, communication, experiences or impact of PE for hospital service improvement, types of PE activities, factors influencing any of these functions, the impact of behavioural interventions to support PE, or the impact of PE. Eligible study designs included English language qualitative (interviews, focus groups, qualitative case studies), quantitative (questionnaires, randomized controlled trials, time series, before/after studies, prospective or retrospective cohort studies, case control studies, economic analyses) or mixed methods studies published in peer-reviewed journals.

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. The following publication types were not eligible: systematic reviews, protocols, editorials, commentaries, letters, news items, or meeting abstracts or proceedings. If more than one publication described a single study and reported different data, they were all included but counted as a single study; if they reported the same data only the most recent publication was included.

## Searching

The search strategy (Supplementary File 1) was developed by ARG (trained as a medical librarian) in conjunction with a professional medical librarian and complied with the Peer Review of Electronic Search Strategy reporting guidelines.[17] MEDLINE, EMBASE, CINAHL, HealthStar and the Cochrane Library were searched on September 20, 2016 for articles published from 2006 to 2016. The year 2006 was chosen to capture the most recent ten years of research given that PE for hospital service improvement is a relatively new phenomenon. Systematic reviews were not eligible but their references and those of all eligible studies were screened to identify additional eligible primary studies. 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]

## Screening

To prepare for screening of titles and abstracts, ARG, LL and AC independently screened titles and abstracts of the first 25 search results, then discussed discrepancies, and how to interpret and apply the eligibility criteria. LL and AC independently screened titles and abstracts according to specified PICO-based eligibility criteria. All items selected by at least one reviewer were retrieved. Full text articles were independently screened by LL and AC prior to data extraction; they consulted ARG weekly to resolve uncertainty in inclusion decisions.

## Data extraction

A data extraction form was developed to collect information on author, publication year, country, research design, number and type of participants, description of PE and/or other intervention, and findings. LL, AC and ARG independently pilot-tested data extraction on three articles and compared findings by discussion to refine the data extraction form. AC and LL independently extracted data from eligible articles; all extracted data were independently checked by ARG.

## Data analysis

Summary statistics were used to describe the number and/or proportion of studies by year published, country, research design, and those that assessed type and extent of PE for hospital service improvement, factors influencing PE, and PE interventions and impact. The type and extent of PE were categorized independently during data extraction using the Carman et al.

framework of patient and family engagement that characterizes PE by level of engagement (own care, organizational design and governance, policy making) and continuum of engagement (consultation, involvement, partnership and shared leadership).[9] For this study, which focused on PE for the organizational design and governance of hospitals, types of PE were organized according to activities that consulted, involved or partnered with patients. The quality of individual studies was not assessed because that is not customary for a scoping review. All co-authors reviewed the summary of findings and their feedback was incorporated in the final version.

## RESULTS

### Search results

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). Data extracted from included studies is summarized in Supplementary File 2.[20-29]

### Study characteristics

Eight of 10 studies reported the number of participating patients (range 10 to 20) and providers (range 18 to 142). Another study included 126 participants but did not report the number of patients and providers;[22] and another study did not report the total number of participants.[28] One study was published in each of 2008 and 2009, and 2 studies per year were published in each of 2010, 2011, 2013 and 2014. Four studies were conducted in the United Kingdom (25.0%), 2 in Australia (16.7%) and 1 (8.3%) in each of Canada, Norway, Taiwan and Uganda. With respect to research design, 4 studies were qualitative case studies most frequently involving interviews and observation, 3 employed qualitative interviews and/or focus groups, and 3 were cross-sectional surveys.[3] Two studies collected data from patients, 3 studies from providers, and 5 studies from both patients and providers.

### Type of PE

All 10 studies identified types of activities in which patients were engaged for hospital service improvement and their roles in those activities. Little detail was provided about precisely what patients were meant to do or did in relation to these activities. 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.[20] 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.[29]. Patients were standing members of quality committees,[20] hospital management committees,[22,28] or advisory panels, councils or networks.[21-23,25,29] They were also members of shorter-term project teams.[20,22,24,25,27] In 3 studies, patients provided solicited feedback by one-time questionnaire or interview about how to improve services.[22,26] In 1 study, patients voluntarily provided feedback about services by mass media or suggestion boxes.[28] In 1 study, patients provided education to other patients.[25] Patients assumed several roles in those activities: developing quality criteria,[20] reviewing quality improvement project results,[20,29] identifying issues that warranted improvement,[20,22,26,28]

suggesting potential solutions for addressing problems,[25] and informing the design or reorganization of services.[20,23,24,27]

Types of PE activities for hospital service improvement were characterized by continuum of engagement (Table 1). Three studies (30.0%) focused on consultation activities: questionnaire, interview, mass media and suggestion boxes.[22,26,28] Eight studies (80.0%) focused on involvement activities: members of standing committees, advisory bodies, project teams or providing education to other patients.[20-25,27,29] One study focused on a partnership where citizen advisory panel recommendations on core services were adopted by a hospital board for a restructuring initiative.[23]

Table 1. Types of PE activities for hospital service improvement [9]

Consultation	Involvement	Partnership and shared leadership
<ul style="list-style-type: none"> <li>• Provide solicited feedback by questionnaire or interview on how to improve services[22,26]</li> <li>• Provide voluntary feedback through mass media or suggestion boxes[28]</li> </ul>	<ul style="list-style-type: none"> <li>• Members of quality committees[20]</li> <li>• Members of hospital management committees[21,28]</li> <li>• Members of advisory panels, councils or networks[21-23,25,29]</li> <li>• Members of project teams[20,22,24,25,27]</li> <li>• Provide education to other patients[25]</li> </ul>	<p>Members of a citizen advisory panel that prioritized core services to inform hospital restricting; recommendations were largely adopted by the hospital board[23]</p>

## Extent of PE

Five (50.0%) studies described the extent to which patients were engaged for hospital service improvement as members of standing committees or project teams. A survey of providers at 74 European hospitals found that patients were infrequently involved in activities such as developing quality criteria or designing or reorganizing services (range 50.0% to 64.8%) and this did not differ across clinical departments.[20] Observation of 10 hospital committee meetings and 11 community network meetings in 8 regions revealed that patient input was minimal; even when they contributed, their influence on decisions was minimal, and their ideas were not pursued by providers subsequent to meetings.[21] 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.[24] A survey of 142 providers who had been on committees with patients revealed that patients did not often fulfill the roles of sharing their experiences, asking difficult questions or improving communication between the health service and the community.[27] Interviews with providers, and focus groups with patients and providers revealed that patients did not perceive themselves to be partners in improving service delivery, and hospital management committees or providers did not use patient feedback.[28]



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**Factors influencing PE**

Seven studies (70.0%) assessed facilitators or barriers to PE for hospital service improvement (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.

Table 2. Factors influencing PE for hospital service improvement

Facilitators	Barriers
<ul style="list-style-type: none"><li>• Selection of patients based on their personal characteristics and skills[24]</li><li>• Involving patients and staff with the desire to work together[24]</li><li>• Involving supportive staff with leverage to navigate hospital processes to effect change[21]</li><li>• Early involvement in projects so that patients were familiar with objectives and could offer meaningful contributions to shape the project’s aims and activities[22]</li><li>• Meeting monthly or more frequently if needed[24]</li><li>• Small team size that was less hierarchical and more easily integrated patients[24]</li><li>• Explicit effort to involve patients in meetings and extend value and respect for their input[22,24,29]</li><li>• Debriefing with patients after meetings to gather feedback about how the session had gone and how interaction could be improved[22]</li><li>• Formal interaction supplemented with informal interaction by email, telephone or other interaction to build relationships[22]</li><li>• Formalizing patient roles by labelling and recognizing their position[22,24]</li><li>• Asking patients about feelings to prompt detailed accounts of their experiences[26]</li><li>• Joint training of patients and health care professionals[22]</li><li>• Patient recommendations that align with what health care professionals consider appropriate[25]</li></ul>	<ul style="list-style-type: none"><li>• Lack of knowledge among health care professionals on how to engage with an empowered group of questioning patients[29]</li><li>• Lack of guidance on the role of patients and how they should be involved[24,27]</li><li>• Health care professional beliefs about the relevance and representativeness of individual patient experiences[21,28]</li><li>• Health care professional beliefs about patient capacity to contribute given lack of criteria for inclusion or a vetting process[24]</li><li>• Health care professional beliefs that patient feedback was complaining and patients were hostile and ungrateful[28,29]</li><li>• Infrequent meetings[24]</li><li>• Disagreement between patients and health care professionals on the role of patients[27]</li><li>• Lack of informal opportunities outside of meetings for interaction to build trust[24]</li><li>• Dysfunction and hierarchies among the health care professionals[24]</li><li>• Pressure from senior management to achieve specific objectives that diverged from patient objectives[29]</li></ul>

Three studies (30.0%) explored the mechanism by which patients influenced the beliefs or actions of providers with whom they interacted. Patient influence appeared to occur through participation in training and meetings with providers,[22] and outside of formal meetings during opportunistic interaction between patients and providers who were supportive and navigated hospital processes to effect change.[21] Patient influence was greater when it provided unique insight on problems that allowed providers to identify new possibilities for solutions compared with patients recommending solutions, and was viewed as particularly valuable when it aligned with what providers viewed as appropriate.[25]

## PE interventions

No studies developed or evaluated behavioural interventions that would promote or support PE for hospital service improvement by influencing patient or provider beliefs or actions.

## PE impact

No studies assessed the impact of PE for hospital service improvement on clinical outcomes. A single study evaluated the impact of PE on participants and health services. Observation of 5 full-day meetings of a 28-member citizen panel convened to establish hospital restructuring priorities and survey of participants after each meeting found they were enthusiastic about the experience, and thought sessions were well organized and the facilitators effective, although some patients were anxious about the magnitude and complexity of the task.[23] Participants thought the panel had accomplished something important that benefited the community and the hospital, and the citizen panel was an effective way to incorporate the community's perspective in decision making. The hospital board approved nearly all panel recommendations resulting in the closure of 26 beds, two outpatient programs, integration of a program with the emergency department, and a transition strategy; changes resulted in a balanced budget in both the 2010-11 and 2011-12 fiscal years.

## DISCUSSION

This scoping review identified few studies published since 2006 that evaluated PE based on consultation, involvement or partnership for hospital service improvement; no studies evaluated interventions that would promote or support PE by influencing patient or provider beliefs or actions. Most studies examined patient involvement in standing committees or projects but few details were provided about those activities. Patient input and influence on decisions was minimal. Only one study evaluated how PE impacted hospital services and no studies evaluated the impact of PE on clinical outcomes. Barriers to PE were primarily at the provider level including negative beliefs and attitudes about patient roles and input, lack of knowledge and skills, provider dysfunction and hierarchies, and uncertainty about how to resolve differences between patient and senior management priorities. Facilitators of PE included joint training of patients and providers, formalizing patient roles, informal interaction to build trust, involving them from the outset of projects, small team size, frequent meetings, active solicitation of patient input during meetings and debriefing after meetings.

The strengths of this study include use of rigorous scoping review methods,[14,15] compliance with standards for the conduct and reporting of reviews,[16] and use of a framework of patient and family engagement to characterize PE activities.[9] 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 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.

The findings of this study concur with previous research based in primary care, which revealed that PE for service improvement was token in nature, thus patients did not inform service design or improvement.[10-12] Barriers (provider beliefs and skills) and facilitators (clearly defined roles for patients, joint training of patients and providers) of PE in the primary care setting also emerged in this study.[10-12] However, this study identified additional barriers and facilitators that may be unique to the hospital context. Identifying barriers and facilitators is an important first step in the selection and tailoring of behavioural interventions for patients and providers that could be implemented to promote and support PE.[30] Having identified barriers and facilitators is particularly important given the paucity of included studies that evaluated behavioural interventions for PE.

This review identified two mechanisms underlying the success of PE for hospital service improvement, both of which may mitigate the lack of skills and negative beliefs among providers that were consistent barriers to PE. These mechanisms should be considered when designing PE activities. One included study found that patient influence on hospital services was more likely when providers were supportive and navigated hospital processes to effect change.[21] It may be crucial to carefully select and/or train providers that participate in committees or project teams with patients so that they function as champions. It is well-recognized that champions can improve service delivery and clinical outcomes,[31] by influencing the knowledge and behavior of their colleagues.[32] Analysis of findings reported 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 to PE (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. Another included study found that patient influence on hospital services was more likely when patients were asked to provide unique insight on problems that allowed providers to identify new possibilities for solutions rather than for patients to recommend solutions that were not viewed by providers as relevant or appropriate.[25] This approach could be accommodated in PE activities that consulted, involved or partnered with patients, appears to a comfortable role that allows patients to express themselves freely and provide detailed accounts of their experiences,[26] and would ensure that providers were engaged rather than alienated by the process.

The value of a scoping review is to reveal issues for which knowledge is lacking that warrant future research. This study identified several such issues. Few types of PE activities for hospital service improvement were examined in included studies. Therefore, ongoing primary research



should develop and evaluate the same and additional types of PE activities. Those activities should address the continuum of PE including consultation, involvement and partnership since all three categories of PE activities may be appropriate for different health service improvement objectives. This review found that patient input and influence on decisions was minimal. Therefore, further primary research is needed to develop and evaluate behavioural interventions that support PE for hospital service improvement 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] One study only examined the impact of PE on participants and health services; no studies assessed the impact of PE on clinical outcomes. Thus, ongoing research that tests the effectiveness of PE behavioural interventions should assess the impact on various individual and organizational outcomes.

## CONCLUSIONS

Few studies have evaluated PE for hospital service improvement to identify the best activities, roles and behavioural interventions for patients and providers that support PE and result in improved health services and patient outcomes. Lack of skill and negative beliefs among providers was a consistent barrier to PE. This review identified numerous facilitators and mechanisms that could be employed by hospitals to optimize PE for service improvement and its impact. Further research is needed to elaborate on PE activities suitable for consultation, involvement and partnership; test behavioural interventions for PE directed at patients and providers informed by the PE barriers and facilitators identified here; and demonstrate the impact of PE. This would identify types of PE activities and supportive conditions that should be prioritized by hospitals.

## COMPETING INTERESTS

The authors have no conflicts to declare

## CONTRIBUTORS

ARG envisioned and planned the study, and provided funding for research assistant support. LL, AC, RU, SES, WW, RB and ARG established study objectives, collected and analyzed or interpreted data, drafted or edited the manuscript, and read and approved the final manuscript.

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## DATA SHARING

All data are available in the manuscript or supplementary files

## ETHICS

All data were publicly available therefore ethics review and approval were not required

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## FIGURE LEGEND

Figure 1. PRISMA diagram

For peer review only

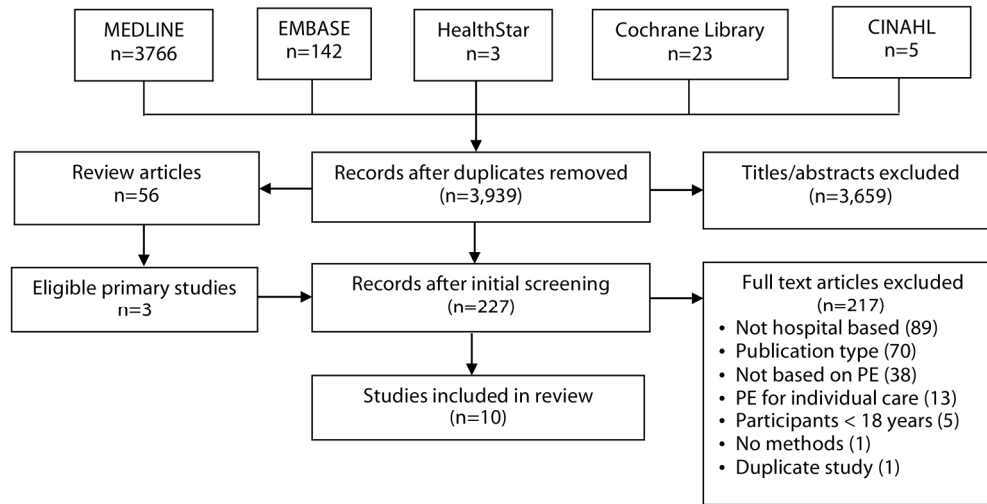


Figure 1. PRISMA diagram

184x94mm (300 x 300 DPI)

Supplementary File 1. Search strategy

- 1 decision making, organizational/ (8026)
- 2 Hospital Planning/mt, og [Methods, Organization & Administration] (408)
- 3 Organizational Objectives/ (14564)
- 4 "organization and administration"/ (2122)
- 5 Patient Care Management/mt, og [Methods, Organization & Administration] (1282)
- 6 Health Services Administration/og [Organization & Administration] (58)
- 7 committee membership/ (556)
- 8 governing board/ (2770)
- 9 institutional management teams/ (1322)
- 10 planning techniques/ (6475)
- 11 organizational innovation/ (17755)
- 12 hospital administration/ (6663)
- 13 Health facility administration/ (1069)
- 14 Professional staff committees/ (1340)
- 15 Health Services Research/mt, og [Methods, Organization & Administration] (5493)
- 16 Program Evaluation/ (44928)
- 17 Quality Assurance, Health Care/mt, og [Methods, Organization & Administration] (10605)
- 18 Quality Improvement/og [Organization & Administration] (2072)
- 19 "Quality of Health Care"/og [Organization & Administration] (3110)
- 20 research/ or behavioral research/ or operations research/ or research design/ (106452)
- 21 Patient-Centered Care/mt, og [Methods, Organization & Administration] (5523)
- 22 Consumer Participation/ (9801)
- 23 Patient Participation/ (15899)
- 24 (patient? adj2 engag\*).tw,kw,ti,ab. (2567)
- 25 (patient? adj2 involv\*).tw,kw,ti,ab. (21062)
- 26 (patient? adj2 participat\*).tw,kw,ti,ab. (10823)
- 27 (famil? adj2 engage\*).tw,kw,ti,ab. (271)
- 28 (famil? adj2 involv\*).tw,kw,ti,ab. (3434)
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- 31 (public? adj2 involv\*).tw,kw,ti,ab. (892)
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- 33 (consumer? adj2 engag\*).tw,kw,ti,ab. (189)
- 34 (consumer? adj2 involv\*).tw,kw,ti,ab. (368)
- 35 (consumer? adj2 participat\*).tw,kw,ti,ab. (266)
- 36 (communit? adj2 engag\*).tw,kw,ti,ab. (1573)
- 37 (communit? adj2 involv\*).tw,kw,ti,ab. (2076)
- 38 (communit? adj2 participat\*).tw,kw,ti,ab. (4233)
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- 40 (user adj2 involv\*).tw,kw,ti,ab. (518)
- 41 (user adj2 participat\*).tw,kw,ti,ab. (167)
- 42 or/1-20 (216918)
- 43 or/21-41 (74443)
- 44 42 and 43 (7674)
- 45 limit 44 to (english language and yr="2006 -Current") (4434)
- 46 limit 45 to (case reports or clinical study or clinical trial, all or clinical trial, phase i or clinical trial, phase ii or clinical trial, phase iii or clinical trial, phase iv or clinical trial or comparative study or controlled clinical trial or pragmatic clinical trial or randomized controlled trial) (668)
- 47 limit 46 to (comment or editorial or interview or lectures or letter or news) (1)
- 48 46 or 47 (668)
- 49 45 not 48 (3766)



## Supplementary File 2. Data extracted from included studies

Author Year Country	Types of PE activities[9]	Objective	Research design	Results
Groene 2014 UK [20]	<u>Involvement</u> <ul style="list-style-type: none"> <li>Members of quality committees</li> <li>Members of project teams</li> </ul>	To describe the involvement of patients in quality management functions	Survey of 72 hospital quality managers and 16 heads of clinical units for clinical pathways for myocardial infarction, stroke, hip fracture, and deliveries in 7 countries: Czech Republic, France, Germany, Poland, Portugal, Spain and Turkey	Most respondents said that patients were never involved in various quality management functions; this did not differ across clinical pathways: <ul style="list-style-type: none"> <li>developing quality criteria (56.7%; p=0.211)</li> <li>designing/organizing processes (60.8%; p=0.217)</li> <li>quality committees (64.8%; p=0.006)</li> <li>quality improvement projects (59.4%; p=0.202)</li> <li>discussion of quality improvement project results (59.4%; p=0.322)</li> </ul>
Nathan 2014 Australia [21]	<u>Involvement</u> <ul style="list-style-type: none"> <li>Members of hospital management committees</li> <li>Members of project teams</li> </ul>	To explore how community members influenced over hospital health service planning and improvement	Qualitative case study involving interviews with 10 community members and 24 hospital managers and observation of meetings of hospital committees (n=10), community member networks (n=11) and the community member council (n=5) from 8 areas	<ul style="list-style-type: none"> <li>Community members said they were deeply committed to making a difference for patients</li> <li>During committee meetings controlled by hospital staff their input was minimal; even when they did contribute to discussions, their influence on decisions was minimal</li> <li>In network meetings that were community-controlled community members raised numerous issues for action; hospital representatives attending these meetings appeared open to the ideas but the ideas were not pursued subsequent to meetings</li> <li>During interviews, staff questioned the representativeness of community members and the relevance of their personal experiences; however, they also identified the value and specific impact of community members on hospital services</li> <li>Community member influence occurred outside of formal meetings during opportunistic interaction with supportive staff who navigated hospital processes to effect change</li> </ul>
Armstrong 2013 UK [22]	<u>Consultation</u> Provide solicited feedback by questionnaire or interview on how to improve services  <u>Involvement</u> <ul style="list-style-type: none"> <li>Members advisory panels,</li> </ul>	To describe patient involvement in quality improvement	Qualitative case study of three projects involving qualitative interviews with 126 patients and providers and observation of meetings across three projects (two based in hospitals, one in primary care)	<ul style="list-style-type: none"> <li>Rationale for involving patients varied: externally mandated, perceived value of patient involvement based on previous work, lack of any previously collected data on the patient experience, belief among providers that capturing the patient experience was important</li> <li>Patients were engaged through a virtual network of patients who could be consulted as required, questionnaires, patient representative on the project team throughout the course of the project, participation in regional meetings, and advisory groups that worked with project teams</li> <li>Facilitators of meaningful involvement were early involvement so that patients could understand the project's aims and shape the work,</li> </ul>

	councils or networks <ul style="list-style-type: none"><li>• Members of project teams</li></ul>			debriefing after meetings to provide feedback on how the session had gone, less formal interaction through email and phone calls, explicit value and respect for input from all team members, and formalizing patient roles <ul style="list-style-type: none"><li>• Patients exerted influence by persuading clinicians that there was an important problem to be addressed and about how it should be addressed; this was largely achieved by participation in meetings and training events with clinicians; and by acting as knowledge brokers to build links between patients and clinicians</li></ul>
Chan 2013 Canada [23]	<u>Involvement</u> <ul style="list-style-type: none"><li>• Members advisory panels, councils or networks</li></ul> <u>Partnership and shared leadership</u> <ul style="list-style-type: none"><li>• Members of a citizen advisory panel that prioritized core services to inform hospital restricting; recommendations were largely adopted by the hospital board</li></ul>	To outline how an Ontario hospital initiated an intensive Citizens' Advisory Panel related to budget and service provision decisions	Qualitative case study (surveys and direct observation)	<ul style="list-style-type: none"><li>• After each CAP session, members were surveyed. Members were enthusiastic about participating, generally thought the sessions were well organized, and agreed the facilitators were effective.</li><li>• There was frustration with the public roundtable in terms of its limited attendance, and the event's representativeness and overall merit.</li><li>• CAP members were also surveyed prior to the board presentation (14 responses, 56% response rate). Although enthusiasm about participation in the panel remained strong, there was also some anxiety because of the magnitude and complexity of the recommendations.</li><li>• A final questionnaire mailed to CAP members after announcements of hospital service changes (12 responses, 48% response rate) found that members generally had a positive view of their experience, thought the panel had accomplished something important, and had been of benefit to the community and the hospital.</li><li>• Overall, 75% of the respondents thought the CAP was an effective way to incorporate the community's perspective in decision making.</li><li>• Some individuals in the public expressed anger about service cuts, although none of the anger was directed at the process or panel members.</li></ul>
Martin 2011 UK [24]	<u>Involvement</u> <ul style="list-style-type: none"><li>• Members of project teams</li></ul>	To explore how patients were involved in working with health care professionals to design and improve patient-centred cancer	Qualitative case study including interviews with 32 staff (physicians, nurses, genetic counsellors, managers) from cancer-genetics services and 12 patients, and observation of 21 meetings across 5 sites	<ul style="list-style-type: none"><li>• At 4 sites, 1 or 2 patients were invited to planning meetings</li><li>• Observation found that patients attended but were largely silent</li><li>• Interviews found that patients felt they were not effectively involved as partners and their suggestions were ignored; staff at these sites agreed</li><li>• Barriers included lack of guidance on the role of patients and how they should be involved; staff suspicion about the capacity of patients to contribute given lack of criteria for inclusion or a vetting process; infrequent meetings; lack of informal opportunities outside of meetings for interaction to build trust; dysfunction and hierarchies among the health care professionals</li><li>• At 1 site patients and health care professionals viewed their work as a genuine partnership</li></ul>

		genetic services		<ul style="list-style-type: none"> <li>Facilitators included selection of patients based on their personal characteristics and skills; the team met monthly and sometimes more frequently if needed; small teams that was less hierarchical and more easily integrated patients; patients and staff were keen to form close, informal bonds that would support their working together; and conscious effort to involve patients in meetings; patients were granted 'volunteer status' by the hospital, which formalized their roles;</li> </ul>
Solbjør 2011 Norway [25]	<u>Involvement</u> <ul style="list-style-type: none"> <li>Members advisory panels, councils or networks</li> <li>Members of project teams</li> <li>Provide education to other patients</li> </ul>	To explore clinician views about the value and involvement of patients in health service improvement	Qualitative interviews with 18 physicians, nurses, other health care professionals and health care managers from 12 regions	<ul style="list-style-type: none"> <li>Patients were involved in user committees that regularly met with management, project groups that worked for limited periods of time, as representatives on regional committees and by providing education to other patients</li> <li>User involvement was viewed as valuable when it provided unique insight on problems that created new possibilities for solutions, and particularly valuable when it aligned with what they viewed as appropriate</li> </ul>
Hsu 2010 Taiwan [26]	<u>Consultation</u> Provide solicited feedback by questionnaire or interview on how to improve services	To evaluate a narrative interviewing approach (story-telling) to collect information from older people about how to improve health care services	Qualitative interviews with 20 patients aged 65 or older in a rehabilitation unit at a single hospital	<ul style="list-style-type: none"> <li>The study found it unhelpful to ask broad questions at the beginning to understand older people's unique meaning attached to health care service; supplemental probe questions offered limited help to understand the narrators' thoughts in relation to their hospital stay experiences</li> <li>Instead, warm-up questions such as "Tell me how you feel when you stay in the hospital?" could help patients express themselves freely and build rapport with the researcher. They found that it was only when narrators were asked about "feelings" that they provided a more detailed account of what they had experienced from their surroundings.</li> <li>Ward meetings and rounds were viewed as the best opportunity to identify and recruit patients connected with nursing notes, reviewing patient assessment records or during nurse handovers.</li> <li>The best time to conduct interviews was immediately after a patient had been notified of their discharge</li> <li>The interviews revealed that nursing assessment skills such as listening and probing could be applied to interviewing older people</li> </ul>
Nathan 2010 Australia [27]	<u>Involvement</u> <ul style="list-style-type: none"> <li>Members of project teams</li> </ul>	To examine health care professional views about the value and roles of community	Questionnaire survey of 142 clinicians and managers from one region that had been on a committee with community members	<ul style="list-style-type: none"> <li>94% of staff had been on a committee with community representation; 26 % had been a chair and 19% had been a support person for community members</li> <li>The most common types of community member influence were strategic planning, priority setting, service design, service delivery, and improved signage and patient information</li> <li>75% said that community members represented the views of the broader</li> </ul>

		members on health service committees		<p>community</p> <ul style="list-style-type: none"><li>• 40% said that community members and health care professionals agreed on the role of community members and 30% said that they understood the community member role and how to work with them</li><li>• Most agreed that community members' role was to improve communication between the health service and the community (98%), share their experiences (60%) and ask difficult questions (59%)</li><li>• Fewer agreed that community members actually fulfilled each of these roles</li></ul>
Rutebemberwa 2009 Uganda [28]	<p><u>Consultation</u></p> <ul style="list-style-type: none"><li>• Provide voluntary feedback through mass media or suggestion boxes</li></ul> <p><u>Involvement</u></p> <ul style="list-style-type: none"><li>• Members of hospital management committees</li></ul>	To explore how hospitals acquired input from community members about hospital services	Qualitative interviews with 8 medical managers and 3 board members, and 8 focus groups with clinicians (n=NR) and 8 focus groups with community members (n=NR) from 8 hospitals in 5 districts	<ul style="list-style-type: none"><li>• Community members were involved in hospital management committees, or provided feedback through mass media like radio or suggestion boxes in hospitals</li><li>• Community members did not see themselves as partners in health care delivery, nor were they recognized as such</li><li>• Each hospital management committee had at least one community member recruited from religious groupings, political leaders or village opinion leaders; the majority of participants thought that these individuals were not representative of the community</li><li>• Hospital management committees did not use feedback from communities nor did community members receive any news from hospitals</li><li>• Community members used FM radio to phone in and share views about hospital services; clinicians and managers thought this was ineffective because the callers complaints were not substantiated and clinicians or managers did not have the opportunity to respond</li><li>• Managers said that feedback from suggestion boxes represented personal opinions and not those of the community; community members said suggestion boxes were not helpful because the very people they talked about were those who would review suggestion box feedback</li><li>• Some clinicians thought that the community was very happy with hospital services; other clinicians felt that the community grumbled but never conveyed their complaints to clinicians and some of those grumbling were ungrateful</li></ul>
Brooks 2008 UK [29]	<p><u>Involvement</u></p> <ul style="list-style-type: none"><li>• Members of advisory panels, councils or networks</li></ul>	To explore the role of patients in a nurse-led advisory council	Qualitative case study involving observation of 14 meetings and interviews with 18 nurses and 17 patients in a single hospital	<ul style="list-style-type: none"><li>• 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</li><li>• Initially there were tensions between nurses and patients on councils</li><li>• Patients had clear ideas about how services could be developed based on their own or their families' experiences, and were frustrated when blocked from offering what they felt was a unique perspective and specialist knowledge</li></ul>

				<ul style="list-style-type: none"> <li>• Nurses felt they instead needed to address specific demands from senior management</li> <li>• Nurses reacted negatively to what they viewed as patient 'story telling' and 'subjective interruptions' that were irrelevant and hindered the smooth running of meetings</li> <li>• Nurses were defensive and described patients as difficult, intimidating, ungrateful and hostile</li> <li>• Nurses admitted to feeling inexperienced and unprepared to engage with an empowered questioning group of patients</li> <li>• Over time conflict was resolved through ongoing discussions at meetings where patients were increasingly given a voice and nurses developed new ways of interacting with patients</li> </ul>
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PE= patient engagement; NR=not reported

PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	See title page
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	2-3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	3
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	3
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Additional File 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	4
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	4
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	4
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	n/a
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	4
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I <sup>2</sup> ) for each meta-analysis.	4



## PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	n/a
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	4
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	5, Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, sex, age, COS, follow-up period) and provide the citations.	5-8, Additional File 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	n/a
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	5-8, Table 1, Table 2
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	n/a
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	5-8, Table 1, Table 2
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome and consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	8
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	9
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	9-10
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	10

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

# BMJ Open

## Patient engagement in hospital health service planning and improvement: a scoping review

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-018263.R2
Article Type:	Research
Date Submitted by the Author:	18-Dec-2017
Complete List of Authors:	Liang, Laurel; University Health Network Cako, Albina; University Health Network Urquhart, Robin; Beatrice Hunter Cancer Research Institute Dalhousie Straus, Sharon; St. Michael's Hospital, Li Ka Shing Knowledge Institute Wodchis, Walter; University of Toronto, Institute of Health Policy Management and Evaluation Baker, Ross; University of Toronto, IHPME Gagliardi, Anna; University Health Network, Toronto General Research Institute
<b>Primary Subject Heading</b>:	Patient-centred medicine
Secondary Subject Heading:	Health policy, Health services research
Keywords:	hospital care, quality improvement, patient engagement, scoping review

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# Patient engagement in hospital health service planning and improvement: a scoping review

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Word count 3,829

# ABSTRACT

## Objectives

Patient engagement improves patient, organization and health system outcomes but most patient engagement research is based on primary care. The primary purpose of this study was to describe the characteristics of published empirical research that evaluated PE in hospital health service improvement.

## Design

Scoping review

## Methods

Five databases were searched from 2006 to September 2016. English language studies that evaluated patient or provider beliefs or participation in patient engagement, or influencing factors or impact were eligible. Screening and data extraction were done in triplicate. PE characteristics, influencing factors and impact were extracted and summarized.

## Results

From a total of 3,939 search results, 227 studies emerged as potentially relevant, of those 217 were not eligible, and 10 studies were included in the review. None evaluated behavioural interventions to promote or support patient engagement. While most studies examined involvement in standing committees or projects, patient input and influence on decisions was minimal. Lack of skill and negative beliefs among providers were patient engagement barriers. Patient engagement facilitators included careful selection and joint training of patients and providers, formalizing patient roles, informal interaction to build trust, involving patients early in projects, small team size, frequent meetings, active solicitation of patient input in meetings and debriefing after meetings. Asking patients to provide insight on problems rather than solutions, and deploying provider champions may enhance patient influence on hospital services.

## Conclusions

Given the important role of patient engagement in improving hospital services and the paucity of research on this topic, future research should develop and evaluate behavioural interventions for patient engagement directed at patients and providers informed by the patient engagement barriers and facilitators identified here, and should assess the impact on various individual and organizational outcomes.

## Systematic Review Registration

None

## Keywords

hospital care, quality improvement, patient-centred care, patient engagement, implementation science, scoping review

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**STRENGTHS and LIMITATIONS**

- By describing the characteristics of published empirical research that evaluated patient engagement (PE) in hospital health service improvement, this research identified what is known about how to achieve PE in hospital health service improvement including facilitators and barriers
- This scoping review also exposed gaps in knowledge that inform future research in this area: develop and evaluate different types of PE along the continuum of consultation, involvement and partnership; develop behavioural interventions targeted at patients and providers to support PE, and evaluate the impact of PE on clinical outcomes
- This study used rigorous scoping review methods including a detailed search of multiple databases that complied with standards for search strategies, employed a framework of patient and family engagement to characterize patient engagement activities, and complied with standards for the conduct and reporting of reviews
- 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
- 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

## BACKGROUND

Patient engagement (PE) in health care is 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] Research has largely focused on engaging patients in securing their own appropriate, effective, safe and responsive health care, also referred to as patient-centred care.[3,4] Previous syntheses of research on PE in their own care generated insight on approaches or technologies to support PE.[5,6] Examples include providing care in a compassionate and empowering manner by sharing information and being sensitive to patient needs,[7] inter-professional collaboration and case management to optimize the coordination of care, and prompting patients to enhance the safety of their own care by reminding health care professionals to use practices such as hand hygiene or the surgical safety checklist.[8]

Patients can also be engaged in designing or improving health services through activities such as completing surveys about their care experiences, or serving as advisors or members of governance or quality improvement committees.[9] 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] However, such ideal environments may not be the norm. A systematic review of 26 studies published from 2000 to 2015 found that barriers of PE in health service improvement were lack of training and uncertainty about role among patients, and health care professional uncertainty about how to work with patients and act on their feedback, resulting in token PE.[11] Similarly, a qualitative systematic review of 11 studies published from 2003 to 2012 found that PE in service improvement was challenged by inadequate planning and differing patient and health care professional views, and that PE was token in most circumstances and did not lead to improvements.[12] Therefore, information is needed on the effective strategies and optimal conditions for PE in service improvement. Such knowledge could provide insight on how to support widespread implementation of PE and greater translation of the patient voice to improved services.

Research on PE in service improvement has thus far largely focused on the primary care setting.[10-12] A considerable proportion of health care is delivered in hospitals, which also seek to optimize service delivery and associated outcomes through PE.[13] Hospital care differs from primary care in setting, conditions/diseases, procedures and providers therefore PE activities, supportive conditions and outcomes may also differ. The quantity and nature of research on PE in hospital-based service improvement has not been previously characterized. The primary purpose of this study was to describe the characteristics of published 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 service improvement PE in the hospital context.

## METHODS

### Approach

Rather than a traditional systematic review that seeks to describe outcomes, a scoping review was conducted.[14,15] This approach was employed to acquire an understanding of the extent, range and nature of research on this topic, describe PE for hospital service improvement and its



determinants and impact, and identify issues that warrant further research. A scoping review involves five steps: scoping, searching, screening, data extraction and data analysis. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses criteria guided the conduct and reporting of this review.[16] Data were publicly available so institutional review board approval was not necessary. A protocol for this review was not registered.

**Scoping**

The scoping step involved becoming familiar with the literature on this topic. A preliminary search was conducted in MEDLINE using Medical Subject Headings including, but not limited to (consumer participation or patient participation) and (program evaluation or quality improvement or hospital administration or hospital planning or health services research). ARG and two trainees (LL, AC) screened titles and abstracts of the search results, which informed the ultimate search strategy and were used to generate eligibility criteria based on the PICO (Population, Intervention, Comparisons, Outcomes) framework. All members of the research team reviewed eligibility criteria and provided feedback, which was used to refine the eligibility criteria. The research team included a physician with expertise in geriatric medicine (SES), health services researchers with expertise in patient safety, quality improvement and PE (WW, RB, SES, RU, ARG) and experts in evidence syntheses (ARG, RU, SES).

**Eligibility criteria**

*Population* referred to both patients and providers. Patients included adults (aged 18+ years) who visited hospitals in any ambulatory, emergent, or inpatient capacity for any health care issue, condition, or disease; or were family members, care givers or well members of the public (all henceforth referred to as patients). Providers were included because research shows that PE is more likely when providers are trained for, and also engaged in PE.[10-12] Providers included any type of clinicians, executives or managers working in hospitals of any type. *Interventions* 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.[9] Interventions also included strategies directed at either patients or providers to promote or support PE in service improvement. With respect to *comparisons*, studies were eligible if they explored ways that patients (or family members/caregivers/public) or providers were involved in PE for hospital service improvement; their views, experiences of, and suggestions to support PE; or evaluated whether and how PE-informed improvements were implemented, strategies used to support PE, or the impact of PE on health services or patient outcomes. Such studies may have included patients or providers with and without exposure to interventions, or before or after exposure to interventions, or receiving different types of interventions. *Outcomes* were any reported by eligible studies and included, but were not limited to, awareness, knowledge, communication, experiences or impact of PE for hospital service improvement, types of PE activities, factors influencing any of these functions, the impact of behavioural interventions to support PE, or the impact of PE. Eligible study designs included English language qualitative (interviews, focus groups, qualitative case studies), quantitative (questionnaires, randomized controlled trials, time series, before/after studies, prospective or retrospective cohort studies, case control studies, economic analyses) or mixed methods studies published in peer-reviewed journals.

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. The following publication types were not eligible: systematic reviews, protocols, editorials, commentaries, letters, news items, or meeting abstracts or proceedings. If more than one publication described a single study and reported different data, they were all included but counted as a single study; if they reported the same data only the most recent publication was included.

## Searching

The search strategy (Supplementary File 1) was developed by ARG (trained as a medical librarian) in conjunction with a professional medical librarian and complied with the Peer Review of Electronic Search Strategy reporting guidelines.[17] MEDLINE, EMBASE, CINAHL, HealthStar and the Cochrane Library were searched on September 20, 2016 for articles published from 2006 to 2016. The year 2006 was chosen to capture the most recent ten years of research given that PE for hospital service improvement is a relatively new phenomenon. Systematic reviews were not eligible but their references and those of all eligible studies were screened to identify additional eligible primary studies. 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]

## Screening

To prepare for screening of titles and abstracts, ARG, LL and AC independently screened titles and abstracts of the first 25 search results, then discussed discrepancies, and how to interpret and apply the eligibility criteria. LL and AC independently screened titles and abstracts according to specified PICO-based eligibility criteria. All items selected by at least one reviewer were retrieved. Full text articles were independently screened by LL and AC prior to data extraction; they consulted ARG weekly to resolve uncertainty in inclusion decisions.

## Data extraction

A data extraction form was developed to collect information on author, publication year, country, research design, number and type of participants, description of PE and/or other intervention, and findings. LL, AC and ARG independently pilot-tested data extraction on three articles and compared findings by discussion to refine the data extraction form. AC and LL independently extracted data from eligible articles; all extracted data were independently checked by ARG.

## Data analysis

Summary statistics were used to describe the number and/or proportion of studies by year published, country, research design, and those that assessed type and extent of PE for hospital service improvement, factors influencing PE, and PE interventions and impact. The type and extent of PE were categorized independently during data extraction using the Carman et al.

framework of patient and family engagement that characterizes PE by level of engagement (own care, organizational design and governance, policy making) and continuum of engagement (consultation, involvement, partnership and shared leadership).[9] For this study, which focused on PE for the organizational design and governance of hospitals, types of PE were organized according to activities that consulted, involved or partnered with patients. The quality of individual studies was not assessed because that is not customary for a scoping review. All co-authors reviewed the summary of findings and their feedback was incorporated in the final version.

## RESULTS

### Search results

From a total of 3,939 unique search results, 2227 full-text studies emerged as potentially relevant, of those 217 did not meet eligibility criteria, and 10 studies were included in the review (Figure 1). Data extracted from included studies is summarized in Supplementary File 2.[20-29]

### Study characteristics

Eight of 10 studies reported the number of participating patients (range 10 to 20) and providers (range 18 to 142). Another study included 126 participants but did not report the number of patients and providers;[22] and another study did not report the total number of participants.[28] One study was published in each of 2008 and 2009, and 2 studies per year were published in each of 2010, 2011, 2013 and 2014. Four studies were conducted in the United Kingdom (25.0%), 2 in Australia (16.7%) and 1 (8.3%) in each of Canada, Norway, Taiwan and Uganda. With respect to research design, 4 studies were qualitative case studies most frequently involving interviews and observation, 3 employed qualitative interviews and/or focus groups, and 3 were cross-sectional surveys.[3] Two studies collected data from patients, 3 studies from providers, and 5 studies from both patients and providers.

### Type of PE

All 10 studies identified types of activities in which patients were engaged for hospital service improvement and their roles in those activities. Little detail was provided about precisely what patients were meant to do or did in relation to these activities. 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.[20] 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.[29]. Patients were standing members of quality committees,[20] hospital management committees,[22,28] or advisory panels, councils or networks.[21-23,25,29] They were also members of shorter-term project teams.[20,22,24,25,27] In 3 studies, patients provided solicited feedback by one-time questionnaire or interview about how to improve services.[22,26] In 1 study, patients voluntarily provided feedback about services by mass media or suggestion boxes.[28] In 1 study, patients provided education to other patients.[25] Patients assumed several roles in those activities: developing quality criteria,[20] reviewing quality improvement project results,[20,29] identifying issues that warranted improvement,[20,22,26,28]

suggesting potential solutions for addressing problems,[25] and informing the design or reorganization of services.[20,23,24,27]

Types of PE activities for hospital service improvement were characterized by continuum of engagement (Table 1). Three studies (30.0%) focused on consultation activities: questionnaire, interview, mass media and suggestion boxes.[22,26,28] Eight studies (80.0%) focused on involvement activities: members of standing committees, advisory bodies, project teams or providing education to other patients.[20-25,27,29] One study focused on a partnership where citizen advisory panel recommendations on core services were adopted by a hospital board for a restructuring initiative.[23]

Table 1. Types of PE activities for hospital service improvement [9]

Consultation	Involvement	Partnership and shared leadership
<ul style="list-style-type: none"> <li>• Provide solicited feedback by questionnaire or interview on how to improve services[22,26]</li> <li>• Provide voluntary feedback through mass media or suggestion boxes[28]</li> </ul>	<ul style="list-style-type: none"> <li>• Members of quality committees[20]</li> <li>• Members of hospital management committees[21,28]</li> <li>• Members of advisory panels, councils or networks[21-23,25,29]</li> <li>• Members of project teams[20,22,24,25,27]</li> <li>• Provide education to other patients[25]</li> </ul>	<p>Members of a citizen advisory panel that prioritized core services to inform hospital restricting; recommendations were largely adopted by the hospital board[23]</p>

## Extent of PE

Five (50.0%) studies described the extent to which patients were engaged for hospital service improvement as members of standing committees or project teams. A survey of providers at 74 European hospitals found that patients were infrequently involved in activities such as developing quality criteria or designing or reorganizing services (range 50.0% to 64.8%) and this did not differ across clinical departments.[20] Observation of 10 hospital committee meetings and 11 community network meetings in 8 regions revealed that patient input was minimal; even when they contributed, their influence on decisions was minimal, and their ideas were not pursued by providers subsequent to meetings.[21] 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.[24] A survey of 142 providers who had been on committees with patients revealed that patients did not often fulfill the roles of sharing their experiences, asking difficult questions or improving communication between the health service and the community.[27] Interviews with providers, and focus groups with patients and providers revealed that patients did not perceive themselves to be partners in improving service delivery, and hospital management committees or providers did not use patient feedback.[28]

## Factors influencing PE



Seven studies (70.0%) assessed facilitators or barriers to PE for hospital service improvement (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.

Table 2. Factors influencing PE for hospital service improvement

Facilitators	Barriers
<ul style="list-style-type: none"><li>• Selection of patients based on their personal characteristics and skills[24]</li><li>• Involving patients and staff with the desire to work together[24]</li><li>• Involving supportive staff with leverage to navigate hospital processes to effect change[21]</li><li>• Early involvement in projects so that patients were familiar with objectives and could offer meaningful contributions to shape the project’s aims and activities[22]</li><li>• Meeting monthly or more frequently if needed[24]</li><li>• Small team size that was less hierarchical and more easily integrated patients[24]</li><li>• Explicit effort to involve patients in meetings and extend value and respect for their input[22,24,29]</li><li>• Debriefing with patients after meetings to gather feedback about how the session had gone and how interaction could be improved[22]</li><li>• Formal interaction supplemented with informal interaction by email, telephone or other interaction to build relationships[22]</li><li>• Formalizing patient roles by labelling and recognizing their position[22,24]</li><li>• Asking patients about feelings to prompt detailed accounts of their experiences[26]</li><li>• Joint training of patients and health care professionals[22]</li><li>• Patient recommendations that align with what health care professionals consider appropriate[25]</li></ul>	<ul style="list-style-type: none"><li>• Lack of knowledge among health care professionals on how to engage with an empowered group of questioning patients[29]</li><li>• Lack of guidance on the role of patients and how they should be involved[24,27]</li><li>• Health care professional beliefs about the relevance and representativeness of individual patient experiences[21,28]</li><li>• Health care professional beliefs about patient capacity to contribute given lack of criteria for inclusion or a vetting process[24]</li><li>• Health care professional beliefs that patient feedback was complaining and patients were hostile and ungrateful[28,29]</li><li>• Infrequent meetings[24]</li><li>• Disagreement between patients and health care professionals on the role of patients[27]</li><li>• Lack of informal opportunities outside of meetings for interaction to build trust[24]</li><li>• Dysfunction and hierarchies among the health care professionals[24]</li><li>• Pressure from senior management to achieve specific objectives that diverged from patient objectives[29]</li></ul>



Three studies (30.0%) explored the mechanism by which patients influenced the beliefs or actions of providers with whom they interacted. Patient influence appeared to occur through participation in training and meetings with providers,[22] and outside of formal meetings during opportunistic interaction between patients and providers who were supportive and navigated hospital processes to effect change.[21] Patient influence was greater when it provided unique insight on problems that allowed providers to identify new possibilities for solutions compared with patients recommending solutions, and was viewed as particularly valuable when it aligned with what providers viewed as appropriate.[25]

## PE interventions

No studies developed or evaluated behavioural interventions that would promote or support PE for hospital service improvement by influencing patient or provider beliefs or actions.

## PE impact

No studies assessed the impact of PE for hospital service improvement on clinical outcomes. A single study evaluated the impact of PE on participants and health services. Observation of 5 full-day meetings of a 28-member citizen panel convened to establish hospital restructuring priorities and survey of participants after each meeting found they were enthusiastic about the experience, and thought sessions were well organized and the facilitators effective, although some patients were anxious about the magnitude and complexity of the task.[23] Participants thought the panel had accomplished something important that benefited the community and the hospital, and the citizen panel was an effective way to incorporate the community's perspective in decision making. The hospital board approved nearly all panel recommendations resulting in the closure of 26 beds, two outpatient programs, integration of a program with the emergency department, and a transition strategy; changes resulted in a balanced budget in both the 2010-11 and 2011-12 fiscal years.

## DISCUSSION

This scoping review identified few studies published since 2006 that evaluated PE based on consultation, involvement or partnership for hospital service improvement; no studies evaluated interventions that would promote or support PE by influencing patient or provider beliefs or actions. Most studies examined patient involvement in standing committees or projects but few details were provided about those activities. Patient input and influence on decisions was minimal. Only one study evaluated how PE impacted hospital services and no studies evaluated the impact of PE on clinical outcomes. Barriers to PE were primarily at the provider level including negative beliefs and attitudes about patient roles and input, lack of knowledge and skills, provider dysfunction and hierarchies, and uncertainty about how to resolve differences between patient and senior management priorities. Facilitators of PE included joint training of patients and providers, formalizing patient roles, informal interaction to build trust, involving them from the outset of projects, small team size, frequent meetings, active solicitation of patient input during meetings and debriefing after meetings.

The strengths of this study include use of rigorous scoping review methods,[14,15] compliance with standards for the conduct and reporting of reviews,[16] and use of a framework of patient and family engagement to characterize PE activities.[9] 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 given the methodological challenges that have been identified by others; as a result, important information may have been missed.[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.

The findings of this study concur with previous research based in primary care, which revealed that PE for service improvement was token in nature, thus patients did not inform service design or improvement.[10-12] Barriers (provider beliefs and skills) and facilitators (clearly defined roles for patients, joint training of patients and providers) of PE in the primary care setting also emerged in this study.[10-12] However, this study identified additional barriers and facilitators that may be unique to the hospital context. Identifying barriers and facilitators is an important first step in the selection and tailoring of behavioural interventions for patients and providers that could be implemented to promote and support PE.[30] Having identified barriers and facilitators is particularly important given the paucity of included studies that evaluated behavioural interventions for PE.

This review identified two mechanisms underlying the success of PE for hospital service improvement, both of which may mitigate the lack of skills and negative beliefs among providers that were consistent barriers to PE. These mechanisms should be considered when designing PE activities. One included study found that patient influence on hospital services was more likely when providers were supportive and navigated hospital processes to effect change.[21] It may be crucial to carefully select and/or train providers that participate in committees or project teams with patients so that they function as champions. It is well-recognized that champions can improve service delivery and clinical outcomes,[31] by influencing the knowledge and behavior of their colleagues.[32] Analysis of findings reported 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 to PE (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. Another included study found that patient influence on hospital services was more likely when patients were asked to provide unique insight on problems that allowed providers to identify new possibilities for solutions rather than for patients to recommend solutions that were not viewed by providers as relevant or appropriate.[25] This approach could be accommodated in PE activities that consulted, involved or partnered with patients, appears to a comfortable role that allows patients to express themselves freely and provide detailed accounts of their experiences,[26] and would ensure that providers were engaged rather than alienated by the process.

The value of a scoping review is to reveal issues for which knowledge is lacking that warrant future research. This study identified several such issues. Few types of PE activities for hospital service improvement were examined in included studies. Therefore, ongoing primary research

should develop and evaluate the same and additional types of PE activities. Those activities should address the continuum of PE including consultation, involvement and partnership since all three categories of PE activities may be appropriate for different health service improvement objectives. This review found that patient input and influence on decisions was minimal. Therefore, further primary research is needed to develop and evaluate behavioural interventions that support PE for hospital service improvement 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] One study only examined the impact of PE on participants and health services; no studies assessed the impact of PE on clinical outcomes. Thus, ongoing research that tests the effectiveness of PE behavioural interventions should assess the impact on various individual and organizational outcomes.

## CONCLUSIONS

Few studies have evaluated PE for hospital service improvement to identify the best activities, roles and behavioural interventions for patients and providers that support PE and result in improved health services and patient outcomes. Lack of skill and negative beliefs among providers was a consistent barrier to PE. This review identified numerous facilitators and mechanisms that could be employed by hospitals to optimize PE for service improvement and its impact. Further research is needed to elaborate on PE activities suitable for consultation, involvement and partnership; test behavioural interventions for PE directed at patients and providers informed by the PE barriers and facilitators identified here; and demonstrate the impact of PE. This would identify types of PE activities and supportive conditions that should be prioritized by hospitals.

## COMPETING INTERESTS

The authors have no conflicts to declare

## CONTRIBUTORS

ARG envisioned and planned the study, and provided funding for research assistant support. LL, AC, RU, SES, WW, RB and ARG established study objectives, collected and analyzed or interpreted data, drafted or edited the manuscript, and read and approved the final manuscript.

## FUNDING

This study was conducted with no source of funding

## DATA SHARING

All data are available in the manuscript or supplementary files

## ETHICS

All data were publicly available therefore ethics review and approval were not required

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## FIGURE LEGEND

Figure 1. PRISMA diagram

For peer review only



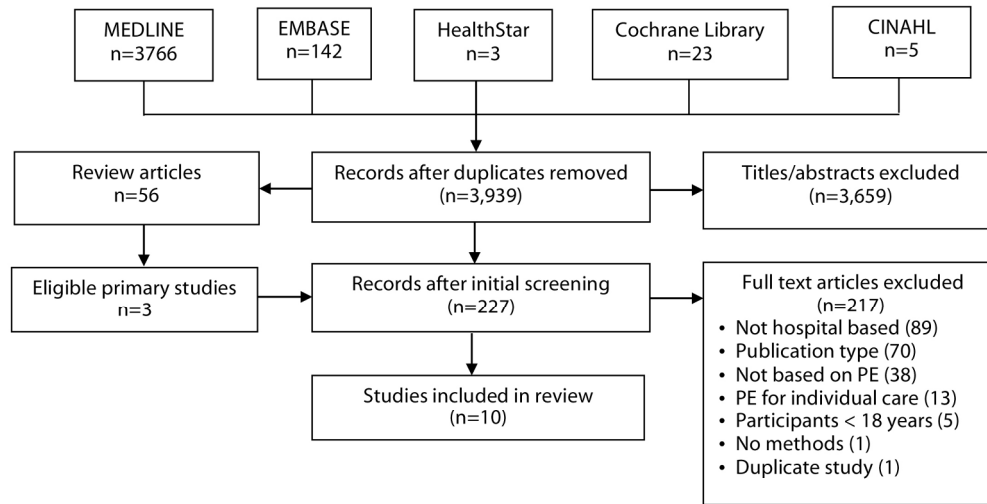


Figure 1. PRISMA diagram

184x94mm (300 x 300 DPI)

Supplementary File 1. Search strategy

- 1 decision making, organizational/ (8026)
- 2 Hospital Planning/mt, og [Methods, Organization & Administration] (408)
- 3 Organizational Objectives/ (14564)
- 4 "organization and administration"/ (2122)
- 5 Patient Care Management/mt, og [Methods, Organization & Administration] (1282)
- 6 Health Services Administration/og [Organization & Administration] (58)
- 7 committee membership/ (556)
- 8 governing board/ (2770)
- 9 institutional management teams/ (1322)
- 10 planning techniques/ (6475)
- 11 organizational innovation/ (17755)
- 12 hospital administration/ (6663)
- 13 Health facility administration/ (1069)
- 14 Professional staff committees/ (1340)
- 15 Health Services Research/mt, og [Methods, Organization & Administration] (5493)
- 16 Program Evaluation/ (44928)
- 17 Quality Assurance, Health Care/mt, og [Methods, Organization & Administration] (10605)
- 18 Quality Improvement/og [Organization & Administration] (2072)
- 19 "Quality of Health Care"/og [Organization & Administration] (3110)
- 20 research/ or behavioral research/ or operations research/ or research design/ (106452)
- 21 Patient-Centered Care/mt, og [Methods, Organization & Administration] (5523)
- 22 Consumer Participation/ (9801)
- 23 Patient Participation/ (15899)
- 24 (patient? adj2 engag\*).tw,kw,ti,ab. (2567)
- 25 (patient? adj2 involv\*).tw,kw,ti,ab. (21062)
- 26 (patient? adj2 participat\*).tw,kw,ti,ab. (10823)
- 27 (famil? adj2 engage\*).tw,kw,ti,ab. (271)
- 28 (famil? adj2 involv\*).tw,kw,ti,ab. (3434)
- 29 (famil? adj2 participat\*).tw,kw,ti,ab. (1146)
- 30 (public? adj2 engag\*).tw,kw,ti,ab. (589)
- 31 (public? adj2 involv\*).tw,kw,ti,ab. (892)
- 32 (public? adj2 participat\*).tw,kw,ti,ab. (723)
- 33 (consumer? adj2 engag\*).tw,kw,ti,ab. (189)
- 34 (consumer? adj2 involv\*).tw,kw,ti,ab. (368)
- 35 (consumer? adj2 participat\*).tw,kw,ti,ab. (266)
- 36 (communit? adj2 engag\*).tw,kw,ti,ab. (1573)
- 37 (communit? adj2 involv\*).tw,kw,ti,ab. (2076)
- 38 (communit? adj2 participat\*).tw,kw,ti,ab. (4233)
- 39 (user adj2 engag\*).tw,kw,ti,ab. (110)
- 40 (user adj2 involv\*).tw,kw,ti,ab. (518)
- 41 (user adj2 participat\*).tw,kw,ti,ab. (167)
- 42 or/1-20 (216918)
- 43 or/21-41 (74443)
- 44 42 and 43 (7674)
- 45 limit 44 to (english language and yr="2006 -Current") (4434)
- 46 limit 45 to (case reports or clinical study or clinical trial, all or clinical trial, phase i or clinical trial, phase ii or clinical trial, phase iii or clinical trial, phase iv or clinical trial or comparative study or controlled clinical trial or pragmatic clinical trial or randomized controlled trial) (668)
- 47 limit 46 to (comment or editorial or interview or lectures or letter or news) (1)
- 48 46 or 47 (668)
- 49 45 not 48 (3766)

## Supplementary File 2. Data extracted from included studies

Author Year Country	Types of PE activities[9]	Objective	Research design	Results
Groene 2014 UK [20]	<u>Involvement</u> <ul style="list-style-type: none"> <li>Members of quality committees</li> <li>Members of project teams</li> </ul>	To describe the involvement of patients in quality management functions	Survey of 72 hospital quality managers and 16 heads of clinical units for clinical pathways for myocardial infarction, stroke, hip fracture, and deliveries in 7 countries: Czech Republic, France, Germany, Poland, Portugal, Spain and Turkey	Most respondents said that patients were never involved in various quality management functions; this did not differ across clinical pathways: <ul style="list-style-type: none"> <li>developing quality criteria (56.7%; p=0.211)</li> <li>designing/organizing processes (60.8%; p=0.217)</li> <li>quality committees (64.8%; p=0.006)</li> <li>quality improvement projects (59.4%; p=0.202)</li> <li>discussion of quality improvement project results (59.4%; p=0.322)</li> </ul>
Nathan 2014 Australia [21]	<u>Involvement</u> <ul style="list-style-type: none"> <li>Members of hospital management committees</li> <li>Members of project teams</li> </ul>	To explore how community members influenced over hospital health service planning and improvement	Qualitative case study involving interviews with 10 community members and 24 hospital managers and observation of meetings of hospital committees (n=10), community member networks (n=11) and the community member council (n=5) from 8 areas	<ul style="list-style-type: none"> <li>Community members said they were deeply committed to making a difference for patients</li> <li>During committee meetings controlled by hospital staff their input was minimal; even when they did contribute to discussions, their influence on decisions was minimal</li> <li>In network meetings that were community-controlled community members raised numerous issues for action; hospital representatives attending these meetings appeared open to the ideas but the ideas were not pursued subsequent to meetings</li> <li>During interviews, staff questioned the representativeness of community members and the relevance of their personal experiences; however, they also identified the value and specific impact of community members on hospital services</li> <li>Community member influence occurred outside of formal meetings during opportunistic interaction with supportive staff who navigated hospital processes to effect change</li> </ul>
Armstrong 2013 UK [22]	<u>Consultation</u> Provide solicited feedback by questionnaire or interview on how to improve services  <u>Involvement</u> <ul style="list-style-type: none"> <li>Members advisory panels,</li> </ul>	To describe patient involvement in quality improvement	Qualitative case study of three projects involving qualitative interviews with 126 patients and providers and observation of meetings across three projects (two based in hospitals, one in primary care)	<ul style="list-style-type: none"> <li>Rationale for involving patients varied: externally mandated, perceived value of patient involvement based on previous work, lack of any previously collected data on the patient experience, belief among providers that capturing the patient experience was important</li> <li>Patients were engaged through a virtual network of patients who could be consulted as required, questionnaires, patient representative on the project team throughout the course of the project, participation in regional meetings, and advisory groups that worked with project teams</li> <li>Facilitators of meaningful involvement were early involvement so that patients could understand the project's aims and shape the work,</li> </ul>

	councils or networks <ul style="list-style-type: none"><li>• Members of project teams</li></ul>			debriefing after meetings to provide feedback on how the session had gone, less formal interaction through email and phone calls, explicit value and respect for input from all team members, and formalizing patient roles <ul style="list-style-type: none"><li>• Patients exerted influence by persuading clinicians that there was an important problem to be addressed and about how it should be addressed; this was largely achieved by participation in meetings and training events with clinicians; and by acting as knowledge brokers to build links between patients and clinicians</li></ul>
Chan 2013 Canada [23]	<u>Involvement</u> <ul style="list-style-type: none"><li>• Members advisory panels, councils or networks</li></ul> <u>Partnership and shared leadership</u> <ul style="list-style-type: none"><li>• Members of a citizen advisory panel that prioritized core services to inform hospital restricting; recommendations were largely adopted by the hospital board</li></ul>	To outline how an Ontario hospital initiated an intensive Citizens' Advisory Panel related to budget and service provision decisions	Qualitative case study (surveys and direct observation)	<ul style="list-style-type: none"><li>• After each CAP session, members were surveyed. Members were enthusiastic about participating, generally thought the sessions were well organized, and agreed the facilitators were effective.</li><li>• There was frustration with the public roundtable in terms of its limited attendance, and the event's representativeness and overall merit.</li><li>• CAP members were also surveyed prior to the board presentation (14 responses, 56% response rate). Although enthusiasm about participation in the panel remained strong, there was also some anxiety because of the magnitude and complexity of the recommendations.</li><li>• A final questionnaire mailed to CAP members after announcements of hospital service changes (12 responses, 48% response rate) found that members generally had a positive view of their experience, thought the panel had accomplished something important, and had been of benefit to the community and the hospital.</li><li>• Overall, 75% of the respondents thought the CAP was an effective way to incorporate the community's perspective in decision making.</li><li>• Some individuals in the public expressed anger about service cuts, although none of the anger was directed at the process or panel members.</li></ul>
Martin 2011 UK [24]	<u>Involvement</u> <ul style="list-style-type: none"><li>• Members of project teams</li></ul>	To explore how patients were involved in working with health care professionals to design and improve patient-centred cancer	Qualitative case study including interviews with 32 staff (physicians, nurses, genetic counsellors, managers) from cancer-genetics services and 12 patients, and observation of 21 meetings across 5 sites	<ul style="list-style-type: none"><li>• At 4 sites, 1 or 2 patients were invited to planning meetings</li><li>• Observation found that patients attended but were largely silent</li><li>• Interviews found that patients felt they were not effectively involved as partners and their suggestions were ignored; staff at these sites agreed</li><li>• Barriers included lack of guidance on the role of patients and how they should be involved; staff suspicion about the capacity of patients to contribute given lack of criteria for inclusion or a vetting process; infrequent meetings; lack of informal opportunities outside of meetings for interaction to build trust; dysfunction and hierarchies among the health care professionals</li><li>• At 1 site patients and health care professionals viewed their work as a genuine partnership</li></ul>

		genetic services		<ul style="list-style-type: none"> <li>Facilitators included selection of patients based on their personal characteristics and skills; the team met monthly and sometimes more frequently if needed; small teams that was less hierarchical and more easily integrated patients; patients and staff were keen to form close, informal bonds that would support their working together; and conscious effort to involve patients in meetings; patients were granted 'volunteer status' by the hospital, which formalized their roles;</li> </ul>
Solbjør 2011 Norway [25]	<u>Involvement</u> <ul style="list-style-type: none"> <li>Members advisory panels, councils or networks</li> <li>Members of project teams</li> <li>Provide education to other patients</li> </ul>	To explore clinician views about the value and involvement of patients in health service improvement	Qualitative interviews with 18 physicians, nurses, other health care professionals and health care managers from 12 regions	<ul style="list-style-type: none"> <li>Patients were involved in user committees that regularly met with management, project groups that worked for limited periods of time, as representatives on regional committees and by providing education to other patients</li> <li>User involvement was viewed as valuable when it provided unique insight on problems that created new possibilities for solutions, and particularly valuable when it aligned with what they viewed as appropriate</li> </ul>
Hsu 2010 Taiwan [26]	<u>Consultation</u> Provide solicited feedback by questionnaire or interview on how to improve services	To evaluate a narrative interviewing approach (story-telling) to collect information from older people about how to improve health care services	Qualitative interviews with 20 patients aged 65 or older in a rehabilitation unit at a single hospital	<ul style="list-style-type: none"> <li>The study found it unhelpful to ask broad questions at the beginning to understand older people's unique meaning attached to health care service; supplemental probe questions offered limited help to understand the narrators' thoughts in relation to their hospital stay experiences</li> <li>Instead, warm-up questions such as "Tell me how you feel when you stay in the hospital?" could help patients express themselves freely and build rapport with the researcher. They found that it was only when narrators were asked about "feelings" that they provided a more detailed account of what they had experienced from their surroundings.</li> <li>Ward meetings and rounds were viewed as the best opportunity to identify and recruit patients complemented with nursing notes, reviewing patient assessment records or during nurse handovers.</li> <li>The best time to conduct interviews was immediately after a patient had been notified of their discharge</li> <li>The interviews revealed that nursing assessment skills such as listening and probing could be applied to interviewing older people</li> </ul>
Nathan 2010 Australia [27]	<u>Involvement</u> <ul style="list-style-type: none"> <li>Members of project teams</li> </ul>	To examine health care professional views about the value and roles of community	Questionnaire survey of 142 clinicians and managers from one region that had been on a committee with community members	<ul style="list-style-type: none"> <li>94% of staff had been on a committee with community representation; 26 % had been a chair and 19% had been a support person for community members</li> <li>The most common types of community member influence were strategic planning, priority setting, service design, service delivery, and improved signage and patient information</li> <li>75% said that community members represented the views of the broader</li> </ul>

		members on health service committees		<p>community</p> <ul style="list-style-type: none"><li>• 40% said that community members and health care professionals agreed on the role of community members and 30% said that they understood the community member role and how to work with them</li><li>• Most agreed that community members' role was to improve communication between the health service and the community (98%), share their experiences (60%) and ask difficult questions (59%)</li><li>• Fewer agreed that community members actually fulfilled each of these roles</li></ul>
Rutebemberwa 2009 Uganda [28]	<p><u>Consultation</u></p> <ul style="list-style-type: none"><li>• Provide voluntary feedback through mass media or suggestion boxes</li></ul> <p><u>Involvement</u></p> <ul style="list-style-type: none"><li>• Members of hospital management committees</li></ul>	To explore how hospitals acquired input from community members about hospital services	Qualitative interviews with 8 medical managers and 3 board members, and 8 focus groups with clinicians (n=NR) and 8 focus groups with community members (n=NR) from 8 hospitals in 5 districts	<ul style="list-style-type: none"><li>• Community members were involved in hospital management committees, or provided feedback through mass media like radio or suggestion boxes in hospitals</li><li>• Community members did not see themselves as partners in health care delivery, nor were they recognized as such</li><li>• Each hospital management committee had at least one community member recruited from religious groupings, political leaders or village opinion leaders; the majority of participants thought that these individuals were not representative of the community</li><li>• Hospital management committees did not use feedback from communities nor did community members receive any news from hospitals</li><li>• Community members used FM radio to phone in and share views about hospital services; clinicians and managers thought this was ineffective because the callers complaints were not substantiated and clinicians or managers did not have the opportunity to respond</li><li>• Managers said that feedback from suggestion boxes represented personal opinions and not those of the community; community members said suggestion boxes were not helpful because the very people they talked about were those who would review suggestion box feedback</li><li>• Some clinicians thought that the community was very happy with hospital services; other clinicians felt that the community grumbled but never conveyed their complaints to clinicians and some of those grumbling were ungrateful</li></ul>
Brooks 2008 UK [29]	<p><u>Involvement</u></p> <ul style="list-style-type: none"><li>• Members of advisory panels, councils or networks</li></ul>	To explore the role of patients in a nurse-led advisory council	Qualitative case study involving observation of 14 meetings and interviews with 18 nurses and 17 patients in a single hospital	<ul style="list-style-type: none"><li>• 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</li><li>• Initially there were tensions between nurses and patients on councils</li><li>• Patients had clear ideas about how services could be developed based on their own or their families' experiences, and were frustrated when blocked from offering what they felt was a unique perspective and specialist knowledge</li></ul>



				<ul style="list-style-type: none"> <li>• Nurses felt they instead needed to address specific demands from senior management</li> <li>• Nurses reacted negatively to what they viewed as patient 'story telling' and 'subjective interruptions' that were irrelevant and hindered the smooth running of meetings</li> <li>• Nurses were defensive and described patients as difficult, intimidating, ungrateful and hostile</li> <li>• Nurses admitted to feeling inexperienced and unprepared to engage with an empowered questioning group of patients</li> <li>• Over time conflict was resolved through ongoing discussions at meetings where patients were increasingly given a voice and nurses developed new ways of interacting with patients</li> </ul>
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PE= patient engagement; NR=not reported

PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	See title page
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	2-3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	3
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	3
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Additional File 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	4
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	4
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	4
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	n/a
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	4
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I <sup>2</sup> ) for each meta-analysis.	4

## PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	n/a
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	4
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	5, Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, sex, age, COS, follow-up period) and provide the citations.	5-8, Additional File 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	n/a
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	5-8, Table 1, Table 2
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	n/a
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	n/a
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	5-8, Table 1, Table 2
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome and consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	8
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	9
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	9-10
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	10

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097