Engaging patients to improve quality of care: a systematic review

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Abstract

Background: To identify the strategies and contextual factors that enable optimal engagement of patients in the design, delivery, and evaluation of health services.

Methods: We searched MEDLINE, EMBASE, CINAHL, Cochrane, Scopus, PsychINFO, Social Science Abstracts, EBSCO, and ISI Web of Science from 1990 to 2016 for empirical studies addressing the active participation of patients, caregivers, or families in the design, delivery and evaluation of health services to improve quality of care. Thematic analysis was used to identify (1) strategies and contextual factors that enable optimal engagement of patients, (2) outcomes of patient engagement, and (3) patients’ experiences of being engaged.

Results: Forty-eight studies were included. Strategies and contextual factors that enable patient engagement were thematically grouped and related to techniques to enhance design, recruitment, involvement and leadership action, and those aimed to creating a receptive context. Reported outcomes ranged from educational or tool development and informed policy or planning documents (discrete products) to enhanced care processes or service delivery and governance (care process or structural outcomes). The level of engagement appears to influence the outcomes of service redesign—discrete products largely derived from low-level engagement (consultative unidirectional feedback)—whereas care process or structural outcomes mainly derived from high-level engagement (co-design or partnership strategies). A minority of studies formally evaluated patients’ experiences of the engagement process (n = 12; 25%). While most experiences were positive—increased self-esteem, feeling empowered, or independent—some patients sought greater involvement and felt that their involvement was important but tokenistic, especially when their requests were denied or decisions had already been made.

Conclusions: Patient engagement can inform patient and provider education and policies, as well as enhance service delivery and governance. Additional evidence is needed to understand patients’ experiences of the engagement process and whether these outcomes translate into improved quality of care.

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Keywords: Patient engagement, Patient involvement, Quality of care, Quality improvement, Health services, Health delivery, Systematic review

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Background
Patient engagement has become a cornerstone of quality of care [1–6] and is a frequently stated goal for healthcare organizations. Traditionally, and most commonly, this engagement has focused on the relationship between patients and providers in making care decisions or how to improve patient efforts to manage their own care [7]. However, there are growing efforts to integrate patients in broader ways, including efforts to improve or redesign service delivery by incorporating patient experiences [8–12]. These efforts are due in part to an increased recognition and acceptance that users of health services have a rightful role, the requisite expertise, and an important contribution in the design and delivery of services [4]. While the nature of patient engagement may vary from including patients as members of a board to time-limited consultation with patients on service redesign, its aims are consistent—to improve the quality of care [11, 13, 14].

Healthcare organizations have a long tradition of measuring the experience of patients, and health service “users” including families, caregivers, and clients, with their services. Yet, traditional satisfaction surveys often prove difficult to translate into improved service delivery [15, 16]. Indeed, research on patient engagement has pointed to the importance of augmenting traditional surveys and complaint processes, moving towards fuller engagement of patients in reviewing and improving the quality of service delivery in institutions and in the community [17–25]. This recognition has been accompanied by a growth in the development of instruments to measure and improve the quality of care patients receive. Over the past two decades, assessments of quality of care from the patient perspective have shifted from patient satisfaction to patient experiences [26]. Increasing literature indicates that it is not only feasible to involve patients in the delivery or re-design of health care [9] but that such engagement can lead to reduced hospital admissions [27], improved effectiveness, efficiency and quality of health services [28–31], improved quality of life, and enhanced quality and accountability of health services [9]. Frameworks of patient involvement have been developed that move from the traditional view of the patient as a passive recipient of a service to an integral member of teams re-designing health care [8, 11]. For example, one framework developed by Bate and Robert (2006) describes a continuum of patient involvement, which ranges from complaints, giving information, listening, and consulting towards experience-based co-design of services [8]. Low-level engagement, such as consulting, comprises largely unidirectional feedback (e.g., focus groups, surveys, interviews), whereas high-level engagement, like co-design, represents a partnership in the design or evaluation of services. A more recent framework developed by Carman et al. describes various levels of engaging patients and families in health and health care, from consultation or involvement to partnership and shared leadership in various activities including direct care, organizational design, and governance to policy-making [11]. Carman’s continuum of engagement was influenced by Arnstein’s formative “ladder of citizen participation,” a continuum of public participation in governance ranging from limited participation to a state of collaborative partnership in which citizens share leadership or control decisions [32].

Governments and health care institutions are urged by some experts to engage patients and other service users, including caregivers and relatives in more robust ways [8, 33] where patients are actively involved as partners or co-leads in organizational re-design and evaluation of health care delivery, as depicted by the red section in Carman’s framework (Fig. 1). Despite the substantive body of research on strategies to engage patients and their effects on patients and health services, the literature is dispersed and has not been recently synthesized into a coherent overview. If the benefits of engaging patients in the design or delivery of health care are to be realized at an organization or system level, then effective strategies and the contextual factors enabling their outcomes need to be identified so that learning can be generalized. We conducted a systematic review of international English language literature on strategies for actively engaging patients and families in improving or redesigning health care and the contextual factors influencing the outcomes of these efforts. The explicit questions that guided our review were:

1. What are the strategies and contextual factors that enable optimal engagement of patients in the design, delivery, and evaluation of health services?
2. What are the outcomes of patient engagement on services?
3. What are patients’ experiences of being engaged?

Methods

Approach
We took a comprehensive approach in our systematic search and included all empirical qualitative, quantitative, and mixed methods study designs across all settings of care to address our narrow research questions. Our review did not fit into typologies of literature reviews [34, 35], given that we included qualitative and quantitative studies (to capture the breadth of studies in this area), employed a thematic analysis (given the multiplicity of designs), and applied a quality appraisal. We followed the PRISMA reporting criteria for Systematic Reviews and Meta-Analyses (Fig. 2) [36].

Search strategy
In accordance with the core principles of systematic review methodology [37], we conducted a systematic
review of relevant literature with the help of a librarian using the electronic databases of: MEDLINE, EMBASE, CINAHL, the Cochrane Library, Scopus, PsychINFO, Social Science Abstracts, AbilInform Business Source Premier (EBSCO), and ISI Web of Science. We searched the databases using the following subject headings related to patient engagement—combinations of “patient”, “user”, “client”, “caregiver”, “family” and “engage”, “participate”, “involve”, “consult”; for those related to designing, evaluating and delivery of services—combinations of “design”,

Fig. 1 Patient engagement frameworks used for the selection and analyses of studies included in our review. The red box indicates the level of engagement along the continuum that is the focus of our studies included in our review [11]. The organizing framework used for analyzing the studies reviewed [8]
“deliver*”, “evaluat*”, “outcome”, “develop*”, “plan*” and “health services”, “health care”, “health”, “service”. We included a combination of search terms from each category for each search, for example, “patient” AND “engage*” AND “design” AND “health services”).

**Criteria for selection**

Studies were eligible for inclusion if they were available empirical articles that explicitly investigated the participation of patients, caregivers, or families in the design, delivery, and evaluation of health services, which aligns with involving or partnering/sharing leadership with patients in organizational design and governance, reflecting Carman’s framework (Fig. 1) [11]. Searches were restricted to qualitative, quantitative, or mixed methods articles published in English between January 1990 and March 2016. We chose 1990 as this coincided with the emergence of patient engagement particularly in mental health services and the broader quality of care discourse. All settings of care were eligible. We excluded articles that did not explicitly address patient engagement, as well as those that did not pertain to the broader design, delivery, and evaluation of health services (e.g., directly engaging patients in patient safety activities such as challenging staff who treat them to wash their hands or monitor the use of a safety checklist in their care, or in their self-management or treatment decisions, or studies pertaining to patient involvement in health research, community development, or health promotion). We also excluded articles that did not describe the outcome of the engagement of patients and those in which the outcomes did not pertain to the design, delivery, or evaluation of health services (e.g., those that related to developing questionnaires or conceptual frameworks, insights on how to engage patients or work collaboratively). We focused on studies that consulted, involved, partnered, or co-designed health services with patients, informed by Bate and Robert’s [8] and Carman et al.’s [11] frameworks on patient engagement (Fig. 1). Finally, theoretical or conceptual articles as well as those focused on guideline development, instrument development, or broader organizational issues were excluded.

Titles and abstracts of the papers were examined to decide if the full article should be retrieved (Fig. 2). EO and CF were the primary reviewers who examined the titles and abstracts, applied inclusion criteria to the articles, and abstracted the data using an abstraction form. Any disagreement and uncertainties regarding inclusion were
discussed and agreed upon by an additional reviewer (YB) on the abstraction form. We conducted calibration exercises to ensure reliability in applying the selection criteria. Reviewers independently screened the titles and abstracts, and discrepancies were discussed and reviewed by the third reviewer. There was a 95.46% observed agreement and 85.75% expected agreement between primary reviewers, with a kappa statistic of 0.703 (standard error, 0.021; 95% confidence interval, 0.662–0.744), which is relatively high compared to other knowledge synthesis protocols reporting 50% consistency rates [34].

Data abstraction and synthesis
Data abstraction forms were used to describe the studies’ population, location (i.e., country), goals, methodology, and outcomes (Table 1); contextual factors influencing engagement (i.e., leadership and specific barriers and facilitators to patient engagement) (Table 2); and patients’ experience with the engagement and evaluation of study quality (Table 3). Studies were then categorized by the level of patient engagement using the Bates and Robert (2006) continuum of patient involvement [8]. Consistent with our aims to review strategies for actively engaging patients and families in improving or redesigning health care, we focused on studies using co-design or those consulting patients but also using elements of co-design—i.e., the more active levels of engagement on the Bates and Robert continuum. We classified changes or products of engaging patients as “quality of care outcomes” and the impact of the engagement on patients as “patients experience outcomes” (Table 1). Quality of care outcomes were categorized into one of the following: developing education or a service-related tool, informing policy or planning documents, and enhancing services or governance. Study quality was assessed by one person and two verifiers using a quality appraisal tool that systematically reviews disparate evidence and methodologies on a scale from “very poor,” “poor,” “fair,” and “good” [38], which reflected the mixed methods articles in our review. Verification involved systematically checking and confirming the fit between each criterion of the assessment tool and the conceptual work of analysis and interpretation of study quality among a subset of studies. We also assessed the possible impact of study quality on the review’s findings (akin to a “sensitivity analysis” conducted for meta-analyses).

Data analysis
Data were analyzed to address the three research questions, with the intention of (1) identifying strategies and contextual factors that enable optimal engagement of patients in the design, delivery, and evaluation of health services; (2) identifying the outcomes of patient engagement; and (3) exploring patients’ experiences of being engaged. YB analyzed the data using quantitative (i.e., frequency analysis) and qualitative methods. YB used thematic analysis to identify the strategies and contextual factors (i.e., barriers and facilitators), outcomes, and experiences of optimal patient engagement. This process involved identifying prominent or recurring themes in the literature (relevant to our research questions) and summarizing the findings of different studies under thematic headings using summary tables. A coding framework was developed to thematically describe the strategies and contextual factors enabling patient engagement. YB and RB refined the framework as new data emerged during the analysis.

Results
Included studies
We found a total of 20,957 studies about involving patients in the design, delivery, or evaluation of health care. Of these, we excluded 20,909 because they did not report outcomes related to health care delivery, design, or evaluation (n = 67) or only informed/consulted with patients, as opposed to engage them in co-design (n = 91) (Fig. 2; Additional file 1: Table S3 & Additional file 2: Figure S1). Our final sample of studies included 48 papers involving patients, families, and caregivers along with service users, health care providers, staff, board members, health care managers, administrators, and decision-makers (Table 1). The publication date of the included studies spanned from 1993 to 2016, and interestingly, co-design was employed as early as 1993 to as recently as 2015 in published studies. Of the 48 included studies, 27 were qualitative studies; 3 were quantitative; 13 constituted mixed methods studies, which included qualitative, quantitative methods; and 5 comprised user panels or advisory meetings (Table 4). We restricted our analysis to articles actively engaging patients. Half of the articles (n = 24) included consultative activities typical of low-level engagement (i.e., where patients provided input on research design or measures as part of the research or administrative team). The other half were co-design (high-level engagement—i.e., deliberative, reflexive processes where patients and providers work together to create solutions [39]) (Table 4). Engagement efforts spanned a range of services, including pediatrics, community and primary care, and most frequently occurred in mental health services (n = 17; 35%—Tables 4 and 1). Studies originated from various countries, with most deriving from the UK (n = 26; 54%) (Tables 4 and 1). Few studies formally evaluated patients’ experiences of the process of being engaged (n = 12; 25%) (Additional file 3: Table S1).

Strategies for optimal patient engagement to improve quality of care
We identified various strategies that contributed to optimal patient engagement, which were mediated by key contextual factors that enabled or constrained the
| Study            | Country | Intervention                                   | Type of service          | Sample size | Level of engagement | Outcomes on quality of care                                                                 | Impact on institution                                                                 |
|------------------|---------|-----------------------------------------------|--------------------------|-------------|---------------------|--------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|
| Acri et al. 2014 | USA     | Community collaboration model Meetings         | Mental health services   | 16          | Consultative to co-design | Developed and implemented screening, education, and an empowerment intervention for peer-delivered services targeted at improving emotional health of low-income new mothers | Users had an equal voice throughout all aspects of building the intervention, which equalized the power differential |
| Barnes 2000      | UK      | Document analysis interviews questionnaire     | Mental health services   | Not clear   | Co-design            | Developed a new program                                                                     | Achieved a culture change towards valuing users’ knowledge, expertise, contributions, and greater power-sharing |
| Barnes and Wistow 1994 | UK     | User panels                                   | Community mental health and disabilities services | Not discussed | Consultative with some co-design | Identified strategies for user involvement; some evidence of service improvements; developed a “change agenda” | Achieved a culture change via “top-down” approach from local authority |
| Berg et al. 2015  | Norway  | User board                                    | Community HIV/AIDS prevention | 7           | Co-design            | Created a design for an outpatient clinic                                                  | Empowerment and autonomy of users through “active citizenship” and a “egalitarian spirit” |
| Blickem et al. 2013 | UK     | Focus groups Interviews Surveys               | Mental health services   | 8 in interviews | Consultative to co-design | Developed and tested a protocol for PLANS, a community-based referral system               | Close engagement of potential users resulted in a grassroots understanding of the support valued by individuals |
| Bone et al. 2013  | USA     | Community-academic advisory committee          | Cancer screening for African Americans | Not discussed | Co-design            | Developed a community health worker model to engage African-American communities in cancer screening and care | Identified the community-academic advisory committee as vital to designing the service and ensuring its effectiveness |
| Brooks 2008      | UK      | Focus groups Interviews Observations          | General health services  | 52          | Co-design            | Patient involvement in auditing processes, development of patient questionnaires, policies, and frameworks | Reinforced the importance of patient narratives and knowledge in organization and delivery of health care |
| Buck 2004        | US      | Citizen advisory board                        | General health services (for homeless individuals) | 7           | Consultative to co-design | Developed informational brochures and recommendations for local interventions and services to improve general health services for the homeless | Achieved collaboration and mutual education |
| Study | Country  | Intervention | Type of service | Sample size | Level of engagement | Outcomes on quality of care | Impact on institution |
|-------|----------|--------------|----------------|-------------|---------------------|----------------------------|----------------------|
| Carlson and Rosenqvist 1990 [51] | Sweden | Consultation meetings Interviews Training course | Diabetes care | 243 | Consultative to co-design | Implementation of care improvement programs and patient information | Identified problems and steps to solve them |
| Cawston 2007 [69] | UK | Focus groups Interviews Questionnaire | Primary care | 72 in focus groups; 372 via questionnaires | Consultative to co-design | Recommendations and some changes made to improve diabetes management in primary care | Created research-community partnerships in evaluating services but had a modest impact on service change |
| Coad 2008 [41] | UK | Youth Council | Pediatrics—acute care youth services | 17 | Co-design | Demonstrated impact of youth council on specific areas of improvement | Identified ways of promoting further involvement |
| Coker et al. 2014 [72] | USA | Community advisory board | Pediatrics | 3 | Co-design | Developed care models for well-child care | Not discussed |
| Elwell 2014 [48] | UK | Group meetings | Acute care | Not discussed | Consultative to co-design | Developed and implemented care pathways for cellulitis care in the hospital | User involvement created the desire to change in the organization |
| Ennis et al. 2014 [70] | UK | Focus groups, interviews, service user planning committee, surveys, usability testing | Mental health services | 121 users via surveys, unclear number via focus groups, 8 users via usability testing, 4 users via service user planning committee | Consultative to co-design | Developed electronic personal health record for mental health patients | Not discussed |
| Enriquez et al. 2010 [67] | USA | Focus groups questionnaires | HIV and intimate partner violence prevention | 7 user partners in design; 31 participants in feasibility study | Co-design | Feasibility of new service was established, which improved protective health behaviors, self-esteem, social support, and attitudes towards partner violence | Delivery of intervention was deemed feasible, community-provider partnership was well received and enhanced acceptability of the intervention |
| Enwin et al. 2016 [71] | USA | Focus groups Interviews Surveys | Pediatrics—asthma | 20 | Consultative to co-design | Developed new protocol and tool for patient discharge | Collaborative model enhanced the perception of ED clinicians as partners in asthma control |
| Factor 2002 [57] | USA | Focus groups | Substance users | 29 | Co-design | Development of a “survival guide” to improve access to treatment | Created and maintained the participation of users in all aspects of guide development |
| Ferreira-Pinto 1995 [58] | Mexico | Interviews Questionnaires | Community HIV/AIDS prevention | 105 | Co-design | Development and implementation of prevention program | Increased self-efficacy and self-esteem of community partners, beyond the program’s outcomes |
| Study                | Country | Intervention                          | Type of service            | Sample size | Level of engagement    | Outcomes on quality of care                                                                 | Impact on institution                                                                 |
|---------------------|---------|---------------------------------------|---------------------------|-------------|------------------------|------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|
| Fitzgerald 2011 [78]| UK      | “Serious game”                        | Mental health services    | 25          | Consultative to co-design | User re-design of layout and furnishings of a new service unit; design of a medication dispensing system | Achieved flexibility and inclusivity through a game format                              |
| Frazier 2007 [42]   | USA     | School-based program                  | Mental health services    | Not discussed | Co-design              | Developed a school-based mental health service program with active engagement of community partners and clinicians | Achieved successful collaboration between community and clinicians on curriculum development |
| Gibson 2005 [60]    | UK      | Interviews, questionnaires, workshops | Pediatric oncology        | 40          | Consultative to co-design | Recommendations for structure and processes of service                                                                 | Not discussed                                                                         |
| Godfrey et al. 2013 [73] | UK | Facilitated workshops, focus groups, interviews | Acute care—delirium Team members, unspecified interviews | 3 delirium prevention team members, unspecified interviews | Consultative to co-design | Prevention of Delirium (POD) program                                                                 | Enhanced culture of caring among staff                                               |
| Hall 2011 [94]      | UK      | Interviews, modeling exercise         | Cancer                    | 18          | Consultative to co-design | Developed a model for shared care of secondary cancer follow-up with general practitioners supported by specialists | Involved service users and deliverers’ experiences in a modeling exercise               |
| Higgins et al. 2016 [95] | Ireland | Action research group, focus groups, peer facilitator, steering committee | Mental health services    | 30 users via focus groups, 21 family members via focus groups | Consultative to co-design | Developed a peer and clinician-led education program                                                                 | Not discussed                                                                         |
| Hopkins and Neimec 2006 [52] | UK | Interviews questionnaires              | Home treatment services   | 70          | Co-design              | Service improvement survey                                                                 | Shared and neutralized power to increase inclusiveness through user participation in process |
| Iedema et al. 2010 [39] | Australia | Interviews                           | Emergency health services | 40          | Co-design              | Recommendations for improving processes and facilities in the ED                                                                 | Created a deliberative space for patients, clinicians, and staff to discuss personal experiences and design processes to ameliorate issues. Process developed new competencies and skills among participants |
| Jones et al. 2008 [62] | UK      | Focus groups, interviews, workgroups  | Stroke services           | 92          | Consultative to co-design | Information package for patients, recommendations for improvements to rehabilitation program; prioritisation of health care issues for stroke patients and development of services | Achieved meaningful user participation in service development through external facilitation |
| Study                                      | Country | Intervention                                      | Type of service          | Sample size | Level of engagement | Outcomes on quality of care                                                                 | Impact on institution                                                                 |
|-------------------------------------------|---------|--------------------------------------------------|--------------------------|-------------|---------------------|---------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| Jones 2010 [96]                           | USA     | Advisory meetings interviews, user testing       | Smoking cessation for deaf individuals | 10          | Consultative to co-design | Developed and tested an Internet-based smoking cessation intervention for deaf individuals in consultation with members of the deaf community | Involved service users in all phases of development and testing                        |
| Lofters et al. 2015 [43]                  | Canada  | Community advisory group, community workshops, concept mapping, interviews | Cancer screening         | 24 via concept mapping | Consultative to co-design | Developed a culturally appropriate cancer screening program for South Asian community delivered via community organizations | Increased capacity to implement evidence-based interventions                           |
| Lord et al. 1994 [63]                     | Canada  | Document analysis, consultation meetings, focus groups, questionnaire | Mental health services   | Not discussed | Co-design | Improved services | Achieved organizational culture change and patient representation on board by broadening power and control through stakeholder involvement |
| Macdonnell et al. 2013 [45]               | Canada  | Brainstorming, facilitated discussions            | Pediatrics—neonatal intensive care | 3           | Co-design | Developed a family integrated care program | Built positive relationships between users and staff                                   |
| MacNeill 2009 [97]                        | UK      | Interviews, observations                         | Pediatrics               | 29          | Consultative to co-design | New model of participation to improve patient-staff relationship and patient understanding of program | Greater involvement of users through democratic process of participation, though users adopted a passive role |
| Mendenhall et al. 2010 [77]               | USA     | Collaborative educational program                | Diabetes                 | 52          | Consultative to Co-design | Collaborative design of a "Family Education Diabetes Series" program, which demonstrated improved outcomes | Achieved collaboration between elders and providers in design and implementation of program through use of talking circles, storytelling, dance, shared meals, and active role in intervention |
| Murphy et al. 2015 [44]                  | Ireland | Quality improvement working teams                | Mental health services   | 10          | Co-design | Enhanced experiences of care for users referred to community mental health services | Acknowledgement that user/family involvement needs to go beyond involvement to true co-production exercises perceived as meaningful by all participating stakeholders |
| Owens 2011 [56]                          | UK      | Workshops                                        | Mental health services   | 12          | Co-design | Developed a text-based intervention for patients who self-harm | Involved users in the design process, which changed the nature of the intervention dramatically |
| Pilgrim and Waldron 1998 [59]             | UK      | Consultation meetings, observations              | Mental health services   | 14          | Co-design | Improved service: extended opening hours, employed a mental health advocate, published an information booklet | Achieved direct negotiations for change between users and professionals |
| Study               | Country | Intervention                               | Type of service | Sample size | Level of engagement | Outcomes on quality of care                                                                                                           | Impact on institution                                                                 |
|---------------------|---------|--------------------------------------------|-----------------|-------------|---------------------|------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| Reeve et al. 2015   | Australia | Focus groups, workshops                     | Primary care    | 6           | Co-design           | Generated new delineation of roles and responsibilities between an Aboriginal community-controlled health service and local Australian health service | Trusting relationship between community and providers as a result of extensive community consultation |
| Rose 2003           | UK      | Questionnaire                              | Mental health services | 221         | Consultative to co-design | Improved coordination of care generally linked to improved user satisfaction                                                          | Very few users were involved or aware of the new coordination process                   |
| Swarbrick et al. 2006| USA     | Group meetings                             | Mental health services | Not discussed | Co-design           | Implementation of the Recovery Network Program, a user-led wellness and recovery training project                                   | Established a collaborative partnership between peer education and hospital staff via user training |
| Thomson et al. 2015 | UK      | “Future” groups                            | Multiple sclerosis | 5           | Co-design           | Reconceptualized service for outpatients                                                                                               | Created a positive working environment with mutual respect and in equal partnership        |
| Todd et al. 2000    | UK      | Interviews                                 | Intellectual disability services | Not discussed | Co-design           | Influenced implementation of service strategy                                                                                         | Achieved a shift in thinking, collaboration and consumer participation in planning         |
| Tollyfield 2014     | UK      | Co-design meetings                         | Acute care—critical care | 19          | Co-design           | Multiple in-unit quality improvement initiatives                                                                                      | Staff reconnected core values of caring and compassion                                   |
| Tooke 2013          | UK      | Service user review panels                 | Dementia        | 14          | Consultative to co-design | Development of organizational priorities and processes for patients with dementia, development of evaluation tools | Enhanced understanding of effective ways for staff to communicate with users               |
| Van Staa et al. 2010| Netherlands | Interviews at a disco party              | Acute care for chronically ill patients | 34          | Co-design to consultative | Recommendations for engaging youth in design and evaluation of health services                                                         | Involving users was feasible and appreciated by users but did not improve quality         |
| Walsh and Hostick   | UK      | Questionnaire                              | Mental health services | 10          | Consultative to co-design | Improved care facility, development of service strategy, and care guide                                                              | Achieved user ownership through external facilitation                                    |
| Weinstein 2006      | UK      | Document analysis, meetings, questionnaire | Mental health services | 72          | Consultative to co-design | Plan to improve service delivery                                                                                                       | Top-down approach of the first case resulted in less user ownership, whereas the collaborative, user-led approach of the second case led to the new approach to seeking users' views and achieved higher response |
| Study                  | Country | Intervention                               | Type of service                  | Sample size                  | Level of engagement | Outcomes on quality of care                                                                 | Impact on institution                                                                 |
|-----------------------|---------|--------------------------------------------|----------------------------------|-----------------------------|--------------------|---------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|
| Wistow and Barnes     | UK      | Consultation meetings, patient council, questionnaire | Mental health and disability services | Not discussed               | Co-design          | Improved access to services: commitment to address issue, employment support unit created | Increased users' voice in their care, which improved the sensitivity of services to individual needs and information about services |
| Xie et al. 2015 [54]  | USA     | Interviews, meetings                       | Acute care                       | 1 parent, 14 stakeholders   | Co-design          | Developed checklist for family-centered rounds                                                | Created buy-in for the family-centered rounds process and need for mutual understanding |
effectiveness of the engagement. These strategies were thematically grouped as techniques to enhance (1) design, (2) recruitment, (3) involvement, (4) creating a receptive context, and (5) leadership actions. Here, we describe the strategies and contextual factors that enabled optimal patient engagement (see also Additional file 3: Table S1).

Techniques to enhance design of engagement
In designing engagements, several studies pointed to the importance of clarifying the objectives, roles, and expectations of the engagement for patients/carers [40–45]. Approaches that gave users specific roles or engaged them in a formal structure such as a steering committee [45] or that enabled patients to set the agenda, develop
Table 3 Quality of care outcomes and levels of engagement

| Type of outcomes                                      | Level of engagement                  | Studies                                                                 |
|-------------------------------------------------------|--------------------------------------|-------------------------------------------------------------------------|
|                                                       |                                      | Co-design                                                               |
|                                                       |                                      | Consultative to co-design                                               |
| Education or tool development                         |                                        | Co-design, co-design                                                    | Pilgrim and Waldron 1998 [59], Factor 2002 [57] |
| Information packages for patients, peers, and providers| Consultative to co-design            | Co-design, co-design                                                    | Jones 2008 [62], Carlson and Rosenqvist 1990 [51], Buck 2004 [76], Ennis 2014 [70], Erwin 2016 [71] |
| Service improvement surveys                          | Co-design, consultative to co-design  | Hopkins and Neirinc 2006 [52], Brooks 2008 [64], Xie 2015 [54]         | Tooke 2013 [49] |
| Informed policy or planning products                  |                                      | Co-design                                                               | Hall 2011 [94] |
| Clinical care models                                  | Consultative to co-design            | Co-design                                                               | MacNeill 2009 [97], Van Staa 2010 [66], Barnes and Wistow 1994 [40] |
| Service/care strategies                               | Co-design                            | Co-design                                                               | Coad 2008 [41] |
| User involvement models                               | Co-design, consultative to co-design  | Todd 2000 [47]                                                         |                                                             |
| Service policy implementation                         | Co-design                            | Co-design                                                               |                                                             |
| Plans or recommendations to improve service delivery  | Co-design, consultative to co-design  | Iedema 2010 [39]                                                       | Jones 2008 [62], Weinstein 2006 [46], Walsh and Hostick 2005 [99], Gibson 2005 [60], Buck 2004 [76], Cawston 2007 [69] |
| Enhanced care process or service delivery             | Co-design                            | PILGRIM and WARDON 1998 [59]                                             |                                                             |
| Employment of a dedicated mental health advocate      | Co-design                            | PILGRIM and WARDON 1998 [59]                                             |                                                             |
| Improved/developed care facilities, services, programs, or intervention | Co-design, consultative to co-design  | PILGRIM and WARDON 1998 [59]                                             |                                                             |
| Improved access to service                            | Co-design                            | Ferreira-Pinto 1995 [58], Frazier 2007 [42], Barnes 2000 [75], Owens 2011 [56], Sawbrick 2006 [55], Lord 1998 [63], Coad 2008 [41], Fitzgerald 2011 [78], Macdonnell 2013 [45], Bone 2013 [93], Berg 2015 [50], Thomson 2015 [68], Reeve 2015 [74], Tolleyfield 2014 [53], Murphy 2015 [44] | Fitzgerald 2011 [78], Jones, 2010 [96], Mendenhall 2010 [77], Walsh and Hostick 2005 [99], Carlson and Rosenqvist 1990 [51], Barnes and Wistow 1994 [40], Cawston 2007 [69], Rose 2003 [98], Godfrey 2013 [73], Blickem 2014 [92], Aci 2014 [65], Higgins 2016 [95], Lofters 2015 [43] |
| Creation of an employment support unit                | Co-design                            | WISTOW and BARNES 1993 [61]                                             |                                                             |
| Creation of new services                              | Co-design                            | WISTOW and BARNES 1993 [61]                                             |                                                             |
| Improved governance                                   | Co-design                            | ENRIQUEZ et al. 2010 [67]                                               |                                                             |

shared mission and purpose statements and participate in all/most stages of the planning, administration, and evaluation made participants feel comfortable with the team and process, maintained patient involvement throughout the course of the process, and improved the quality of outcomes [41, 45–50]. These techniques occurred in mental health, HIV, and pediatric service settings where patients were engaged to improve access to, and quality of, care or promote a culture change in the development and delivery of services.

An important strategy used in pediatric, diabetes, and home care settings was holding training sessions to prepare staff and patients, which provided clarity on roles and responsibilities, helped patients or carers understand how they could best contribute, sensitized participants to the contextual and cultural issues, and increased patients’ confidence and commitment to the engagement process [41, 51, 52]. Training also offered the benefit of building positive relationships between users, facilitators, and staff [43, 45, 49, 53, 54], which also served to mitigate a key barrier identified: providers’ skepticism towards
engaging patients and devolving power to them [42, 55]. Therefore, these techniques helped to create a level playing field and support staff in their efforts to be partners.

Techniques to enhance representation

With respect to sampling and recruitment, several studies stressed the importance of ensuring diversity and representation consistent with the broader population across different professional backgrounds and skills [43, 45, 54]. These studies endorsed recruiting patients through providers, [42] existing patients [56], and those with broader networks or previous working relationships with staff [45, 54, 57, 58]. These techniques proved useful in engaging patients in the context of HIV/AIDS prevention, interventions to reduce repetition of self-harm and substance use, and identifying barriers to mental health services [42, 56–58]. One caveat with this approach is that it needs to be weighed against the potential for introducing biases or including self-selected participants. Offering stipends, financial compensation (e.g., child care, transportation), or other incentives encouraged participation [42, 45, 50, 54, 55, 58, 59]. One study in the HIV setting used creative techniques to incentivize participation beyond monetary incentives, such as counseling, access to medical care, and granting diplomas [58].

Techniques to enhance involvement

Several authors also endorsed flexible approaches for involving patients [45, 49, 53, 54]. For example, Gibson et al. [60] used peer reporter interviews (where patient pairs interviewed each other), headline generation (where phrases were created to capture important issues), group discussion (using a Who, Why, When, What, How structure), a written exercise, and questionnaires for non-attendees to find out what youth would like from their follow-up pediatric oncology services. Other techniques identified in studies were the inclusion of higher proportions of patients compared to providers or staff to give patients a stronger voice in the discussion and process [61] and building in debriefing to provide feedback on how suggestions were acted upon to increase the accuracy of the findings and offer an opportunity for additional input. These techniques proved useful in engaging patients to prioritize stroke service issues and document the process of change of a mental

Table 4 Characteristics of patient engagement studies

| Study characteristics (n = 48) | Number | Percent |
|------------------------------|--------|---------|
| Country                      |        |         |
| UK                           | 26     | 54      |
| USA                          | 11     | 23      |
| Canada                       | 3      | 6       |
| Australia                    | 2      | 4       |
| Ireland                      | 2      | 4       |
| Mexico                       | 1      | 2       |
| Sweden                       | 1      | 2       |
| Netherlands                  | 1      | 2       |
| Norway                       | 1      | 2       |
| Type of service              |        |         |
| Mental health                | 17     | 35      |
| General health/community/primary care | 5 | 10 |
| Pediatric/maternity care     | 6      | 13      |
| Acute care/emergency         | 6      | 13      |
| Cancer                       | 3      | 6       |
| HIV/AIDS                     | 3      | 6       |
| Diabetes                     | 2      | 4       |
| Smoking cessation/substance abuse | 2 | 4 |
| Physical and intellectual disability | 1 | 2 |
| Elderly/home treatment       | 1      | 2       |
| Stroke                       | 1      | 2       |
| Multiple sclerosis           | 1      | 2       |
| Design                       |        |         |
| Qualitative                  | 27     | 56      |
| Mixed methods                | 13     | 27      |
| Quantitative                 | 3      | 6       |
| Other                        | 5      | 11      |
| Level of engagement          |        |         |
| Co-design                    | 24     | 50      |
| Consultative to co-design    | 24     | 50      |
| Type of quality of care outcome* | | |
| Discrete product             |        |         |
| Education/tool development   | 11     | 23      |
| Enhanced policy or planning document | 15 | 31 |
| Care process or structural outcome | | |
| Enhanced care process or service delivery | 35 | 73 |
| Enhanced governance          | 5      | 10      |
| Evaluation of patient experiences of engagement process | | |
| Formal                       | 12     | 25      |
| Informal; anecdotal reports  | 11     | 23      |
| None                         | 25     | 52      |

*The total outcomes exceed the number of studies because some studies reported more than one outcome
health organization [62, 63]. Others built in regular updates to patient support group to elicit more views, thereby broadening the reach and involvement of patients and providing opportunities to raise and discuss issues of concern in informal settings [48, 54]. One creative technique was a buddy system for users/families to ensure their participation at meetings and throughout implementation/evaluation of a quality improvement project in mental health services [44].

**Techniques to create a receptive context**

Several studies across general medicine, diabetes, mental health, and emergency services highlighted the importance of creating a receptive context by giving each of the stakeholder groups equal say, using techniques such as deliberation and democratic dialog, [39, 51] values and beliefs exercise [48], and narratives to facilitate shared understandings, generate consensus, or find common ground [54, 64]. These techniques created a level playing field and supported staff in their efforts to be partners. Other studies focused on the empowerment and autonomy of users through “active citizenship” in an “egalitarian spirit” [50, 65] which was found to foster a culture of respect [54]. Ensuring that users had an equal voice throughout all aspects of building the intervention was found to help equalize the power differential that often arises in professionally delivered services [65]. Finally, location influenced participation—some studies held consultation outside of the hospital setting such as a disco to appeal to youth [66]. Others conducted meetings in participants’ homes [58] and childcare community sites [67].

External facilitation [39, 63] catalyzed receptive contexts that encouraged user involvement by creating a positive working environment with mutual respect and equal partnership [53]. Finally, attention was also paid to the physical environment (e.g., cleanliness, chair arrangement [53]) and use of physical props, and visual mapping, which supported participants’ discussion and interactions as well as demonstrated to service users the importance of their contribution [68].

**Leadership actions**

A key facilitator of successful engagement was actions and involvement by organizational leaders. This occurred in a variety of ways including top-down approaches and at community levels where local champions led initiatives or were actively engaged to ensure their success. Top-down approaches included institutional- or executive-level commitment and sponsorship, which was readily apparent across mental health, HIV, and pediatric care settings [41, 44–46, 50, 63]. Having managers and executives recognize and advocate for the importance of patient involvement fostered a sense of empowerment and commitment among patients and ensured organizational sustainability of the engagement. This was a goal of two mental health studies, where the senior level of a local authority took a “top-down” approach to promote user involvement, which resulted in a reported culture change throughout the authority [40, 63]. This was highlighted in one study’s “ideological and policy commitment to meaningful involvement of people affected with HIV” as demonstrated by ongoing contact with management and executives and a head clinician open to changes that would disturb traditional relationships and power disparities between service users and providers [50]. Leadership action was also shown to help align the engagement findings or recommendations and ensure that they are advanced within the organization’s relevant strategic plans and policies in primary care [69]. Timing is also an important factor—ensuring that the engagement occurs prior to decision-making, rather than providing input on proposals to which services are already committed was stressed in a number of studies [45]. Otherwise, the engagement could run the risk of being perceived as tokenistic by the users.

**Outcomes of engaging patients to improve quality of care**

**Discrete outcomes of improved quality of care**

Most studies noted more than one type of outcome on the quality of care, including enhanced care or service delivery (n = 35), development of specific policy or planning documents (n = 15), and enhanced governance and education or tool development (n = 5 and 11, respectively). Examples of educational materials, tools, policy, and planning documents included evaluation tools [49], electronic personal health records for mental health users [70], a new tool for discharge [71], creation of models of care [72], and organization priorities and processes [49]. Examples of care process, service delivery, and governance included the creation of a prevention of delirium program [73], family integrated program in NICU [45], and care pathway for cellulitis that reduced admissions to hospital [48]. Other engagements in this category led to complete organizational redesign of an outpatient HIV clinic in Southern Norway [50], reconceptualized service for outpatients [68], and revisions to the delineation of roles and responsibilities between an Aboriginal community-controlled health service and local Australian health service [74].

We conceptualized the development of educational materials, tools, policy, and planning documents as “discrete products,” whereas enhanced care process, service delivery, and governance constituted “care process or structural outcomes.” Interestingly, discrete products were more likely to derive from studies using lower levels of engagement (i.e., mostly consultative with elements of co-design), while care process or structural
outcomes were more likely to result from higher levels of engagement (i.e., co-design) (Table 3).

**Impact of engaging patients on the institution**
Engaging patients can also change the culture of staff and care settings. The experiences reported in these articles included shifts in organizational culture promoting further patient participation in service design and delivery, [40, 63, 75] achieving collaboration and mutual learning, [42, 47, 76, 77] and sharing or neutralizing power among patients and providers or staff, [52] as well as developing new competencies and negotiating for service changes [39, 59] (Table 4). Interestingly, these outcomes tended to arise in mental health settings and from co-design engagements (Table 5). Further analysis of the methods used in these studies revealed key enabling factors including creating deliberative spaces to share experiences, including external facilitation; broadening power and control to include users, values, and beliefs exercises; conducting user/staff/provider training; and implementing a top-down approach from the local authority (Table 5).

**Table 5** Examples of studies reporting the impact of engaging patients in institutions

| Reference | Level of engagement | Service type | Patient engagement outcome | Method/facilitator |
|-----------|---------------------|--------------|---------------------------|-------------------|
| Acri et al. 2014 [65] | Consultative to co-design | Mental health | Shared/neutralized power | Equal voice of users and organization |
| Barnes 2000 [75] | Co-design | Mental health | Culture change | Educational program |
| Barnes and Wistow 1994 [40] | Consultative to co-design | Mental health | Culture change | Top-down approach from the local authority |
| Buck 2004 [76] | Consultative to co-design | General health | Collaboration and mutual learning | Citizen advisory board |
| Elwell 2014 [48] | Consultative to co-design | Acute care | Organizational impetus to change | User group meetings |
| Frazier 2007 [42] | Co-design | Mental health | Collaboration between community and clinicians | Service model development |
| Godfrey et al. 2013 [73] | Consultative to co-design | Acute care | Culture change | Program development |
| Hopkins and Neimec 2006 [52] | Co-design | Home tx services | Shared/neutralized power | Users conducted research/interviews |
| Iedema 2010 [39] | Co-design | Emergency services | Development of new competencies | Created deliberative space to share experiences |
| Jones 2008 [62] | Consultative to co-design | Stroke services | Meaningful user participation | External facilitation |
| Lord 1994 [63] | Co-design | Mental health | Culture change | Broadening power and control |
| Macdonnell et al. 2013 [45] | Co-design | Pediatrics | Enhanced relationship between users and providers | Program development |
| Mendenhall 2010 [77] | Consultative to co-design | Diabetes | Collaboration between community and providers | Talking circles, storytelling, giving users active role |
| Pilgrim and Waldron 1998 [59] | Co-design | Mental health | Direct negotiations for change | Empowering users and external facilitation |
| Reeve et al. 2015 [74] | Co-design | Primary care | Enhanced relationships between community and providers | Extensive community consultation |
| Swarbrick 2006 [55] | Co-design | Mental health | Collaborative partnership | User training |
| Thomson et al. 2015 [68] | Co-design | Multiple sclerosis | Mutual understanding | Program development |
| Todd 2000 [47] | Co-design | Intellectual disability | Shift in thinking, collaboration, and participation | Higher proportion of users to providers, training, and clarity of roles |
| Tollyfield 2014 [53] | Co-design | Acute care | Reconnection to core values of caring and compassion | Ongoing co-design meetings |
| Tooke 2013 [49] | Consultative to co-design | Dementia | Enhanced communication between users and providers | Service user panels |
| Walsh and Hostick 2005 [89] | Consultative to co-design | Mental health | User ownership | External facilitation |
| Xie 2015 [54] | Co-design | Acute care | Commitment and mutual understanding | Familiar, experienced user representatives, establishing common ground and updating users on progress |
Patients’ experiences of being engaged to improve quality of care
Twenty-three of the 48 studies provided information on the patients’ experiences of their engagement, though only 12 studies formally evaluated patients’ experiences in the process of being engaged to improve quality of care. Of those that evaluated experiences, ten studies reported positive views, while in two studies, patients reported negative experiences and two studies reported both positive and negative experiences (Additional file 3: Table S1). Of the positive experiences, patients and carers expressed satisfaction with the engagement processes [43, 78] were interested in continuing their involvement in the longer term, [75] felt the experience to be educational, [52] and felt that participation highlighted issues that would have otherwise been ignored [39, 64, 75]. Positive experiences were linked to feeling empowered and independent as a result of skills development and positive recognition [58, 59, 63]. Some patients reported increased self-esteem from contributing [41, 58, 66] and improved self-efficacy and self-sufficiency [76] and that the experience encouraged peer educators to pursue formal training [55]. In another study, staff reported learning about user participation [46].

Patient feedback in other engagement studies was not as positive. Some studies found that patients were satisfied but felt the engagement demanded considerable energy and time [66]. Others felt that their involvement was tokenistic because decisions had been made in advance or was used to justify decisions that had already been made [47, 61]. Some participants felt that their requests were denied or that managerial support was lacking [47], while others were dissatisfied with their lack of involvement in analyzing the findings and creating the final report [46].

Quality appraisal
The average quality of the studies was “fair,” based on a quality appraisal tool that systematically reviews disparate forms of evidence and methodologies on a scale from “very poor,” “poor,” “fair,” and “good” [38] (Additional file 4: Table S2). We also assessed the possible impact of study quality on the review’s findings (akin to a “sensitivity analysis” conducted for meta-analyses). There were only 6 (of 48) “poor” quality studies. Removing the six poor quality studies reduced the number/range of examples provided for our findings on the strategies/contextual factors that contributed to optimal patient engagement (research question 1), their outcomes on services (research question 2), and patients’ experience of being engaged (research question 3), but deletion of these studies from the analysis did not alter the substance of the findings.

Discussion
This study provides a comprehensive review of the strategies used to engage patients in service planning, design, and evaluation. It also identifies the outcomes and contextual factors shaping optimal patient engagement to improve quality of care. Strategies and contextual factors that enabled patient engagement included techniques to enhance design, recruitment, involvement, and leadership action, and those aimed at creating a receptive context. Reported outcomes ranged from developing education or tools for patients and providers and informing policy or planning documents (discrete products) to enhanced care, service delivery, and governance (care process or structural outcomes). Interestingly, the level of engagement appears to influence the outcomes of service redesign: discrete products largely derived from low-level (consultative) engagement, whereas care process or structural outcomes mainly derived from high-level (co-design) engagement. Surprisingly, only a minority of studies (n = 12; 25%) formally evaluated patients’ experiences of the engagement activities. While most experiences were positive, some patients sought greater involvement and felt that their involvement was important but tokenistic, especially when requests were denied or when the engagement was used to justify decisions that had already been made. However, it remains unclear how these initiatives affect patients and whether these improvements translate into improved quality of care at a system level.

There were several limitations to this review. Despite the large number of initial search results, there was only a small number of studies focused on involving patients in co-designing health service improvement. Therefore, despite our best attempts, the specificity of our search criteria was modest, a problem familiar to systematic reviews in health services research, which typically crosses many disciplinary boundaries [38]. Future searches would benefit from improved keywords or MeSH terms on the topic of patient engagement. In addition, studies characterized health service users and their involvement differently, ranging from user-centeredness, patient-centered care, and user involvement to patient involvement or participation. Indeed, “user” was a common term used in the UK, whereas other terms such as “patient” and “caregiver” are commonly used in the USA and Canada. These different conceptualizations might signify important distinctions, and the use of different terms, and the publication of these papers across many different journals, raises challenges in identifying and analyzing this literature. We addressed this limitation by using multiple terms and search strategies across multiple disciplinary databases that incorporated terms used in similar reviews. We deliberately sought out the terminology used in key articles to expand our search though may not have captured the entire breadth of terms, such as “consumer,” a popular term used in Australian health services research. We echo previous work that identified this “conceptual muddle” as “one of
the greatest barriers to truly integrating patient involvement into health services, policy, and research” [79].

There was also significant variation in sample sizes and populations included in these engagement studies. Samples sizes ranged from 3 to 372 participants and included a variety of patients, families, caregivers, service users, health care providers, staff, board members, health care managers, administrators, and decision-makers. Many studies did not provide details on their sample. These variations illuminate the absence of a standard approach for designing and reporting engagement initiatives. This variation may also reflect the variety of journals in which this research is reported. Additional limitations include the variety of methods used and the limited evaluation of the engagement methods themselves. Where there was no explicit evaluation of engagement, other information including authors’ discussion of strengths and limitations was used to assess the effectiveness of engagement. However, this does not specifically comprise evaluation of the engagement process or its outcomes on care. Development of evaluative metrics and frameworks for the procedural and substantive outcomes of engagements appears warranted. A final important limitation is that our search ended in 2016, and therefore, these insights may differ in the future given the rapidly growing field of patient engagement. This is a limitation familiar to systematic reviews but a future review may be warranted.

Despite these limitations, our study revealed key insights into the factors that influence the ability of health care organizations and decision-makers to create opportunities for engagement that are not provided in individual studies, which cross disciplines and geographical boundaries. We found that successful patient engagement resulted in culture change within the organization, meaningful collaboration and mutual learning, and shared or neutralized power, which tended to arise in settings where co-design is used. Optimal engagement often includes some of the following strategies: use of deliberative spaces to share experiences, external facilitation, broadening power and control to include users in all aspects of the process, flexible approaches for involving users, user training, clarity of roles and objectives, providing feedback, leadership by local champions and securing institutional and/or executive level commitment, and sponsorship from local authority by way of dedicated resources and on-going contact with management and executives. Leadership is key, but there may be a potential temporal trend in leadership actions; top-down approaches to patient engagement tended to be reported in earlier studies [40, 63] whereas more clinician or community-driven initiatives emerged from more recent studies [42, 77]. Another important factor is the timing of engagement. If the engagement occurred after a decision had been made, the success (or even function) of the engagement became highly questionable from the patient’s perspective. Taken together, this analysis suggests that co-design methods supported by executive sponsorship or driven by local champions that use externally facilitated, deliberative, experience-based discourse with trained users can promote successful patient engagement and outcomes.

Mental health settings emerged as a frequent venue for patient engagement in our review. The earliest reports in our review [61, 63, 80] are in this setting, suggesting that the therapeutic approaches, the nature of the population, or the orientation of mental health services might encourage greater patient participation in this area. Indeed, enabling service user involvement in care planning is a key principle of contemporary mental health guidance in the UK [81] and a potentially effective method of improving the culture and responsiveness of mental health services in light of a service history founded on aspects of containment and compulsion, and the stigmatization of those using mental health services [82]. Many of the co-design engagement activities that led to staff and organizational changes such as improved collaboration and mutual learning [42, 47, 76, 77], sharing or neutralizing power among patients and providers or staff [52], developing new competencies, and negotiating for service changes [39, 59] also occurred in mental health. While patient engagement is now occurring in many settings, the experiences in mental health settings serve as important examples of effective patient engagement.

Ultimately, the effectiveness of any patient engagement should be judged by its impact on patient care. There is a growing body of literature that indicates that engaging patients can lead to improved effectiveness, efficiency, quality of care [28–31], health outcomes, and cost-effective health service utilization [27, 83, 84]. The outcomes reported in our review spanned beyond improved care to include enhanced governance and informed policies and organizational planning, which illustrates the breadth of quality of care initiatives that might be sought through patient engagement. However, drawing causal associations between engaging patients in health services improvement and health outcomes is difficult. Furthermore, it remains unclear whether these improvements translate into sustained or improved quality of care beyond local settings at a system level. Indeed, one study found a lack of evidence that patient involvement leads to the implementation of patient-centered care [85]. Some evaluative tools are emerging [86], yet more studies are needed that assess the conditions on which these tools and strategies can sustain the quality of care systemically.

Our review builds upon previous reviews in this field by providing insight into the associations between quality improvement methods and the varying system-level
outcomes they yield. Indeed, our review echoes previous research indicating that patient engagement can lead to a multiplicity of health services outcomes with sufficient role definition, training, and alignment of patient-provider expectations but that the quality of the reporting has been poor and the full impact of patient engagement is not fully understood [87–89]. Previous reviews have been limited to specific countries [87], care settings (e.g., mental health [89]), hospitals [90], or study design (e.g., qualitative studies [88]). In this way, our review provides a comprehensive perspective of optimal strategies used internationally, across care settings and using multiple methodologies to engage patients, caregivers, and relatives in quality of care improvement initiatives. Our review also provides novel insights into how the level of engagement influences the outcomes, namely, discrete products (e.g., development of tools and documents) largely derived from low-level engagement (consultative unidirectional feedback), whereas care process or structural outcomes (e.g., improved governance, care or services) mainly derived from high-level engagement (co-design or partnership strategies). If the benefits of engaging patients in the design or delivery of health care are to be realized at an organization or system level, then effective strategies and the contextual factors enabling their outcomes need to be identified so that learning can be generalized. Importantly, our review provides guidance on the effective strategies and contextual factors that enable patient engagement including techniques to enhance the design, recruitment, involvement, and leadership action, and those aimed to create a receptive context.

Future research would benefit from greater consistency in the conceptual, methodological, and evaluative frameworks employed. Greater emphasis is also needed on a procedural evaluation that assesses group composition, group cohesion or collaboration, equality of the participation, and the level of deliberation/reasoning. Such assessments are being developed in the deliberative democracy field [91] and could be informative in patient engagement initiatives. The limited evaluation of patients’ experiences is particularly ironic given the intent of these services to be patient-centered. Additional evaluative metrics should be developed to examine patients’ experiences. Finally, since it is difficult to draw causal relationships between patient engagement and health outcomes, future research should incorporate longitudinal measures and approaches to explore the impact of patient co-design on quality of care.

Several practice implications also emerge and reflect factors linked to the success of quality improvement initiatives more generally. Senior leadership support is critical to success since it increases the likelihood that the relevant decision-makers will implement the findings, and dedicated resources may encourage staff commitment to these efforts.

Conclusions
Despite the substantive body of research on strategies to engage patients and their effects on patients and health services, the literature is varied and dispersed. This study provides a comprehensive review of the strategies used to engage patients in service planning and design, identifies the outcomes, and contextual factors shaping optimal patient engagement to improve quality of care. Patient engagement can inform education, tools, planning, and policy (discrete products) as well as enhance service delivery and governance (care process or structural outcomes). The level of engagement appears to influence the outcomes of service redesign; discrete products are largely derived from low-level (consultative to co-design) engagement, whereas care process or structural outcomes mainly derived from high-level (co-design) engagement. Further evidence is needed to understand patients’ experiences of the engagement process and whether these outcomes translate into improved quality of care.

Additional files

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Authors’ contributions
YB and GRB conceived of the study and participated in its design and coordination. KO and PB retrieved the records. EO, CF, and PB screened the records. EO and CF extracted the data from the eligible articles. YB and GRB developed the initial interpretations of the data and participated in the data analysis. SC conducted the quality appraisal. YB drafted the manuscript. YB
and RB revising the manuscript. J-LD and M-PP were involved in the study design and oversight; they reviewed the initial data analyses and suggested revisions to the versions of the manuscript. All authors read and approved the final manuscript.

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Not applicable.

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