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Building patient capacity to participate in care during hospitalization: A scoping review

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Manuscripts

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3 **Building Patient Capacity to Participate in Care during Hospitalization:**
4 **A Scoping Review**
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Abstract

Objectives: To map the existing literature by describing interventions aimed at building the capacity of patients to participate in care during hospitalization by: a) describing and categorizing the aspects of care targeted by these interventions; and b) identifying the Behavior Change Techniques used in these interventions. A patient representative participated in all aspects of this project.

Design: Scoping review.

Data sources: MEDLINE, Embase and CINAHL (Inception -2017).

Study Selection: Studies reporting primary research studies on building the capacity of hospitalized adult patients to participate in care which described or included one or more structured or systematic intervention and described the outcomes for at least key stakeholder group were included.

Data Extraction: Title and abstract screening and full text screening was conducted by pairs of trained reviewers. One reviewer extracted data, which was verified by a second reviewer. Interventions were classified according to seven aspects of care relevant to hospital settings. Behavior change techniques identified in the articles were assigned through consensus of three reviewers.

Results: Database searches yielded a total 9,899 articles, resulting in 87 articles that met the inclusion criteria. Interventions directed at building patient capacity to participate in care while hospitalized were categorized as those related to improving: patient safety (20.9%); care coordination (5.7%); effective treatment (5.7%); and/or patient-centred care using: bedside nursing hand-overs (5.7%); communication (29.1%); care planning (14%); or the care environment (19.8%). The majority of studies reported one or more positive outcomes from the reported intervention. Adding new elements (objects) to the environment and restructuring the social and/or physical environment were the most frequently identified Behavior Change Techniques.

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3 **Conclusions:** The majority of studies to build capacity for participation in care report one or more
4
5 positive outcomes, although a more comprehensive analysis is warranted.
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9 **Strengths and Limitations of the Study**
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- 13 • A comprehensive scoping review related to building the capacity of hospitalized patients to
14 participate in care was conducted.
 - 15
16 • Identification of behavior change techniques used in included studies highlights the importance
17 of behavior change as foundational in interventions designed to build hospitalized patient
18 capacity to participate in care.
 - 19
20 • Because building capacity of hospitalized patients to participate in care can take many forms,
21 the aims, interventions and study designs included in this review were heterogeneous and
22 largely descriptive.
 - 23
24 • As the quality of evidence related to building capacity of hospitalized patients to participate in
25 care advances, conclusions regarding the effectiveness of specific interventions will become
26 possible.
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41 **Keywords:** Patient participation; patient-centred care: behavior change techniques; hospitals; quality
42 improvement
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44 Word Count: 3680
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1. Introduction

Improving the safety, quality and patient-centredness of care delivered in hospitals is well-recognized as a global priority^{1,2}, with increasing recognition of the potential of patient engagement to contribute to the improvement agenda.^{3,4} Patient engagement is defined by the WHO as “the process of building the capacity of patients, families, carers and health care providers, in order to enhance safety, quality and patient-centredness of health care delivery”.⁵

Effective engagement of patients in care provided during hospitalization has been associated with better self-management,⁶⁻⁷ fewer adverse events,⁸ and diagnostic tests,⁹ decreased use of health services,¹⁰ and shorter lengths of stay.¹¹ Patients and families who are engaged in care have opportunities to provide information essential to appropriate care planning,¹² to recognize errors in care deliver,¹³ and to adhere to treatment plans.¹⁴ Additional benefits of effective patient and family engagement include: enhancing system responsiveness to evolving user needs¹⁵; promoting decision-making transparency and improving quality^{16,17}; and reducing cost and waste.¹⁵

The quality challenges common to health care systems include the need to improve patient safety, patient-centred care, care coordination, effective prevention and treatment, healthy living and care affordability.¹⁸ Within hospital settings, high acuity and rapid patient turn-over represent barriers to effective patient participation in care to an extent not found in other health care settings. Wide variability in the implementation of practices designed to promote patient and family engagement was identified in a survey of U.S. hospitals.¹⁷ These practices were classified into the following categories: a) organizational (e.g. formal policy for disclosing medical error); b) bedside (e.g. participation in shift change report); and c) access to information and shared decision-making (e.g. online access to personal health information).

Better understanding of the characteristics of interventions aimed at building the capacity of hospitalized patients to participate in care is important for building the evidence base in this area and

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3 strengthening the theoretical underpinnings of future interventions at the design phase. Successful
4 implementation of these types of interventions may be facilitated by the incorporation of systematic
5 methods such as behavior change techniques (BCTs) for characterizing interventions and linking these to
6 an analysis of the targeted behavior.^{19, 20} BCTs are defined as “observable, replicable and irreducible
7 component[s] of an intervention designed to alter or redirect causal processes that regulate behavior”.

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14¹⁹ The BCT Taxonomy can offer a reliable and systematic framework for the identification of the “active,
15 effective” components within specific interventions¹⁹, provided sufficient detail is provided about the
16 intervention.²¹

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21 Given the dynamic state of evidence describing interventions to promote patient participation, a
22 scoping review was the most appropriate method to produce a narrative integration of relevant
23 evidence addressing our broadly defined question.²¹ Although efforts to intentionally build capacity to
24 participate in care have become a priority in many hospitals, much remains to be learned about how to
25 best accomplish this goal. *In order to advance the evidence base in this area, this scoping review aims to*
26 *map the existing literature describing interventions aimed at building the capacity of patients to*
27 *participate in care during hospitalization.* Our specific research questions were to: a) describe and
28 categorize the aspects of care targeted by these interventions; and b) identify the behavior change
29 techniques used in the interventions to build patient participation in care.

30 31 32 33 34 35 36 37 38 39 40 41 **2. Methods**

42 43 44 *2.1 Design*

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47 As one form of knowledge synthesis, scoping reviews provide narrative integration of relevant
48 evidence by mapping key concepts, types of evidence and gaps in research to address a broad question
49 investigating a particular field.²² To date, there have been no syntheses of the interventions designed to
50 build capacity of hospitalized patients to participate in care.
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3 This systematic scoping review has allowed us to determine the extent, range and nature of
4 research activity related to initiatives designed to build the capacity of hospitalized patients to
5 participate in care. Guided by the methodology proposed by Arksey and O'Malley²² and its subsequent
6 revisions,^{23,24} this review included the following steps: a) identifying the research question; b)
7 identifying relevant studies; c) describing study selection criteria; d) charting the data; and e) collating,
8 summarizing and reporting the results. In keeping with other scoping reviews in which the research
9 team is large and multi-disciplinary,²⁵ we did not undertake the optional step of consultation. Because
10 scoping reviews seek to understand topics of significant complexity in a broad area, rather than
11 synthesize only the best available evidence, a quality appraisal of included studies was not performed.²¹

22 **Patient and Public Involvement**

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26 Given our focus on patient engagement, our interdisciplinary team also included a retired
27 university professor (MS) with an education background who provided input from the perspective of a
28 patient.²⁶ This individual contributed actively to all phases of this scoping review, sharing his
29 experiences within the system and contributing to our interpretation of the findings.

30 *2.2 Identifying the Research Question*

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40 In collaboration with knowledge users from the provincial Health Quality Council and health
41 region, as well as decision makers from the Ministry of Health, the team identified the following
42 question as the focus for this scoping review: **What are the characteristics of interventions designed to**
43 **build the capacity of hospitalized patients in addressing key health care priorities reported in the**
44 **literature?**

45 *2.3 Identifying Relevant Studies*

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3 Following an initial scan of potentially relevant databases, MEDLINE, Embase and CINAHL were
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5 selected for use in this review as having the best coverage of literature related to hospitals. A
6
7 comprehensive electronic literature search was conducted by an experienced medical librarian (EW) in
8
9 MEDLINE, Embase and CINAHL from inception to December 15, 2016 and updated August 31, 2017. Our
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11 search strategy included the following key terms and synonyms: acute care; hospitals; caregivers;
12
13 family; and patient participation, empowerment, engagement or involvement. Please see
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15 Supplementary File 1 for the comprehensive search strategy in MEDLINE. The reference lists of studies
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17 were examined to identify additional relevant articles.
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21 Literature search results were uploaded into Covidence™ Systematic Review Software ²⁷ after
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23 removing duplicate references. This software provides a decision dashboard and annotation tool, as well
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25 as the capacity to create forms for screening and extracting data. Additional duplicates missed by the
26
27 reference software were removed as identified. Studies were selected in two phases: a) title and
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29 abstract screening and b) full text screening/review.
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32 33 *2.4 Study Selection* 34 35

36 Inclusion and exclusion criteria were developed based upon a preliminary literature review and
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38 the advice of knowledge users and decision-makers. In order to be included in this scoping review, the
39
40 studies must have: a) taken place within a hospital setting (including inpatient rehabilitation); b)
41
42 described or included a structured or systematic approach to building capacity of patients to participate
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44 in care, including organizational practices, bedside practices or access to information practices; d)
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46 included adults patients only and e) described the outcomes of the interventions from any one of the
47
48 following stakeholder perspectives: patients and families; health care providers; health systems; or
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50 administrators/funders. We included only studies published in English for this scoping review, as this
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52 was the primary language spoken by team members.
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3 Papers addressing interventions to build capacity in the following populations were excluded:
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5 children and adolescents; community or home settings; oncology patients (because this group often
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7 experiences rapid transitions between community, outpatient and inpatient settings) and Emergency
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9 Department settings. We also excluded papers focused upon: patient participation in research,
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11 databases, quality improvement (e.g. patient advisory councils) or health care service re-design; patient
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13 needs, knowledge or activation assessments.
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17 Team training sessions for reviewers consisted of group screening of 20 titles. The inclusion and
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19 exclusion criteria were pilot-tested during the training session resulting in minor revisions to enhance
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21 the clarity of descriptors and improve inter-rater reliability. Following this training, titles and abstracts
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23 were screened by two reviewers, one of whom was the PI (DG).²⁶
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27 A second team training session for full text screening and review was held. Eight of the nine
28
29 team members participated in full text screening and review, with EP serving as an arbitrator. Two
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31 researchers independently reviewed each of articles selected for full-text screening to ensure inclusion
32
33 criteria had been met. Discrepancies were discussed between the researchers to achieve consensus and
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35 in one case, the dispute was resolved by the arbitrator.
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38 39 *2.5 Charting the Data*

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41 A standard data extraction form created using Microsoft Word (Supplementary File 2) was pilot-
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43 tested in the team training session prior to data extraction. Use of this software, rather than the pre-set
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45 categories in Covidence, allowed us flexibility in data extraction categories and entries. Pairs of team
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47 members were randomly assigned to extract data from 20 articles. Key characteristics extracted from
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49 each article included: a) study identification (author, year of publication, setting, country); b) focus of
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51 the intervention; c) description of the intervention; d) study design and participants; and e) study
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53 findings. All extracted data from each pair of team members were reviewed and confirmed by DG.
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3 In order to categorize the focus of each article, reviewers initially coded each article according to
4 the terms used by the authors (e.g. multidisciplinary goal setting). Two team members (DG and CH)
5 then assigned each article to one of seven categories adapted from the AHRQ National Quality Strategy
6 Priorities¹⁸ that reflected dominant themes of this corpus of literature: patient safety; care
7 coordination; effective treatment; bedside nursing hand-overs; communication; care planning; and the
8 care environment.
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17 Coding of BCT categories and techniques occurred following the data extraction. Each article
18 was re-read by DG, MM and LN. BCT codes were assigned independently using the operational
19 definitions provided by the BCT taxonomy v1¹⁹ and the supplementary BCT coding framework reported
20 by Presseau et al.²⁰ There was no limit on the number of BCTs that could be identified. Discrepancies in
21 BCT assignment were discussed and consensus achieved.
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28 29 *2.6 Collating, summarizing and reporting the results*

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32 A narrative approach was used to collate, summarize and report the data. Summary statistics
33 were used to describe the number of studies by setting, country, year of publication, methods, focus
34 and BCTs identified.
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38 39 **3. Results**

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42 A total of 9,899 articles (9,239 on December 15, 2016 and 660 in the search update on August
43 31, 2017) were identified after duplicates were removed through the search process (Figure 1).
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45 Following title and abstract screening, 503 remaining articles met our inclusion criteria and underwent
46 full-text screening. During the full-text assessment, 416 were excluded because they did not meet one
47 or more of the eligibility criteria (n= 319), did not report on a specific intervention (n= 36), or were
48 conference abstracts (n=61).
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3.1 Characteristics of included studies

Supplementary Table 3 presents the summary of included studies (n=87).²⁸⁻¹¹⁵ Over half of these studies originated in either the U.S. (n=32, 36.8%) or the U.K. (n=17, 19.5%). Fifteen (17.2%) came from Scandinavian countries and eight from Australia (9.2%). Only five (5.7%) articles were published prior to 2000.

3.1.1 Study designs

The studies included were methodologically diverse. Of the 87 included articles, three (3.4%) were randomized controlled trials examining outcomes of interventions designed to build patient capacity to participate in care coordination³⁸, communication⁶⁶ and effective treatment.¹⁰⁷ Three (3.4%) cluster randomized controlled trials aimed at improving patient capacity to participate in safety initiatives⁸⁰, recognize deteriorating condition¹⁰⁴, and the care environment.¹¹³

The remaining studies included quasi-experimental designs, case-controlled studies (including the use of administrative data), interrupted time series, ethnographies, case studies, chart reviews and pre- and post-test designs. Qualitative and mixed methods approaches (n=29, 33.3%) and cross-sectional or pre- and post- interventions surveys (n=21, 24.1%) were used in over half of the included studies.

3.1.2 Patient populations

While a significant proportion of capacity-building interventions (e.g. safety, rapid response teams) were implemented across entire acute care hospitals, other studies were directed towards specific patient populations, such as critically ill (n=7, 8.0%)^{33, 50, 54, 69, 71, 83, 95}, geriatric (n=6, 6.9%)^{51, 76, 84, 90, 101, 113}, rehabilitation (n=9, 10.3%)^{46, 67, 68, 87, 95, 102, 106, 114, 115}, surgical (n=6, 6.9%)^{62, 70, 107, 110, 111} or psychiatric (n=8, 9.2%)^{32, 56, 66, 85, 93, 98, 99, 108} patients.

3.1.3 Outcomes

Positive outcomes were reported in two of the randomized controlled trials^{38, 66} and two of the cluster randomized controlled trials^{104, 113}. Failure to achieve key study objectives were reported in a number of the remaining studies.^{31, 48, 75, 80, 83, 85, 94, 98, 110} The remaining studies reported one or more positive outcomes associated with the intervention to build hospitalized patient capacity to engage in care.

3.2 Aspects of care addressed by capacity-building interventions

Interventions designed to build patients' capacity to participate were found to address seven key aspects of care in hospitals. These aspects of care included: patient safety (n=18; 20.7%); bedside nursing handovers (n=5; 5.7%); communication (n=25; 28.7%); care planning (n=12; 13.8%); modifications to the care environment to promote engagement (n=17; 19.5%); care coordination (n=5; 5.7%) and effective treatment (5; 5.7%).

The interventions focused on patient safety addressed a range of safety issues including: medications^{28, 37, 58, 75, 112}; falls^{28, 51, 67}; hand-washing^{28, 44, 45, 52, 82, 88}; surgical site identification²⁸; medical error⁷⁸; or patient reporting and action^{30, 75, 80, 86, 91, 96}. Eleven (12.6%) studies incorporated a form of information technology to build the capacity of patients to participate in care.

One-third of the included studies (n=25, 28.7%) reported interventions designed to enhance communication between patients and providers to promote participation in care. Examples include interventions designed to encourage interactions between patients, families and providers^{33, 42, 50, 69}, to provide a means by which patients or families could communicate their wishes or concerns^{72, 73, 79, 83} or to share clinical information with patients.^{31, 59, 64, 70, 95}

Multi-component programs aimed at enhancing the environment in which patient-and family-care was delivered accounted for 17 (19.5%) studies. These interventions often involved new models of care specifically aimed at promoting patient-centredness using multiple interventions, such the adoption of new standards of care.⁷⁷

3.3 Behavior Change Techniques Identified to Build Patient Capacity to Participate in Care

Table 1 describes the types of behavior change techniques used to build capacity for each of the seven key aspects of care.

Table 1. Behavior Change Techniques Identified to Build Patient Capacity to Participate in Care (n=87)

Aspect of Care	References	BCT
Patient Safety (n=18)	28	Shaping knowledge Antecedents (adding objects to the environment)
	30	Antecedents (restructuring the physical and social environment; adding objects to the environment)
	37*	Antecedents (adding objects to the environment)
	44	Shaping knowledge Antecedents (adding objects to the environment)
	45	Shaping knowledge Antecedents (adding objects to the environment)
	51*	Antecedents (adding objects to the environment)
	52	Shaping knowledge Antecedents (adding objects to the environment)
	58	Antecedents (adding objects to the environment)
	67	Shaping knowledge Feedback and monitoring Repetition and Substitution (behavioral practice/ rehearsal)
	75	Shaping knowledge Antecedents (adding objects to the environment)
78	Antecedents (restructuring social environment) Shaping knowledge Repetition and substitution Comparison of behavior (demonstration)	
80	Antecedents (adding objects to the environment) Feedback and monitoring	

	82	Antecedents (adding objects to the environment) Feedback and monitoring Association (prompts and cues)
	86	Antecedents (adding objects) Feedback and monitoring
	88	Feedback and monitoring Shaping knowledge
	91	Antecedents (restructuring the social environment) Shaping knowledge
	96	Antecedents (adding objects to the environment) Shaping Knowledge Comparison of behavior (demonstration)
	112	Antecedents (restructuring the social environment)
Person- and Family-Centred Care: Bedside Nursing Handovers (n=5)	29	Shaping knowledge Antecedents (adding objects to the environment)
	35	Antecedents (restructuring the physical and social environments) Scheduled consequences
	74	Antecedents (restructuring the social environment)
	89	Antecedents (restructuring social environment)
	103	Shaping knowledge Antecedents (restructuring social environment; adding objects to the environment)
Person- and Family-Centred Care: Communication (n=25)	31*	Antecedents (adding objects to the environment)
	33	Shaping knowledge Social Support
	42*	Goals and planning Antecedents (restructuring the social environment; adding objects to the environment)
	46	Goals and planning
	48	Feedback and monitoring Antecedents (Adding objects to the environment)
	50	Antecedents (restructuring social environment)
	53*	Antecedents (restructuring the social environment; adding objects to the environment)
	59*	Antecedents (restructuring the social environment; adding objects to the environment)
	60	Shaping knowledge Antecedents (adding objects to the environment)
61*	Antecedents (adding objects to the environment)	

	63	Feedback and monitoring Antecedents (restructuring social environment; adding objects to the environment)
	64*	Antecedents (adding objects to the environment) Shaping knowledge Feedback and monitoring
	66	Shaping knowledge Repetition and Substitution (behavioral practice) Feedback and monitoring
	69	Shaping knowledge Antecedents (restructuring the social environment; adding objects to the environment)
	70	Shaping knowledge Antecedents (adding objects to the environment)
	72	Feedback and monitoring Antecedents (restructuring the social environment; adding objects to the environment)
	73	Feedback and monitoring Antecedents (restructuring the social environment; adding objects to the environment)
	79	Goals and Planning Antecedents (adding objects to the environment)
	83	Shaping knowledge Antecedents (restructuring the social environment)
	84	Antecedents (restructuring the social environment)
	92*	Shaping knowledge Antecedents (adding objects to the environment)
	95	Shaping knowledge Antecedents (restructuring the social environment; adding objects to the environment)
	101	Shaping Knowledge Antecedents (adding objects to the environment) Goals and Planning Feedback and monitoring
	105	Antecedents (adding objects to the environment) Goals and Planning
	108	Antecedents (restructuring the social environment)
Person- and Family-Centred Care: Care Planning (n=12)	40*	Feedback and monitoring Antecedents (adding objects to the environment)
	43	Goals and planning Antecedents (restructuring the social environment)
	47	Goals and planning Antecedents (restructuring the social environment)
	49	Goals and Planning

	54*	Antecedents (adding objects to the environment)
	71	Antecedents (restructuring the social environment)
	94	Antecedents (restructuring the social environment)
	100	Antecedents (restructuring the social environment)
	109	Antecedents (restructuring the social environment) Goals and Planning
	110	Antecedents (restructuring the social environment) Feedback and monitoring
	114	Goals and Planning Antecedents (restructuring the social environment)
	115	Goals and Planning Antecedents (restructuring the social environment) Social support
Person- and Family Centred Care: Care Environment Programs (n=17)	32	Goals and Planning Antecedents (restructuring the social environment)
	34	Goals and planning Feedback and monitoring Antecedents (restructuring the physical and social environments)
	56	Feedback and monitoring (Self-monitoring of behavior) Antecedents (restructuring the social environment)
	57	Antecedents (restructuring the social environment; adding objects to the environment) Social support
	62	Shaping knowledge Natural consequences
	65	Social support Antecedents (restructuring the social environment)
	76	Shaping knowledge Antecedents (adding objects to the environment) Social support
	77	Antecedents (restructuring the social environment; adding objects to the environment) Goals and Planning
	85	Social Support Antecedents (Restructuring the social environment)
	90	Goals and Planning Antecedents (restructuring the social environment)
	97	Antecedents (restructuring the social environment)
	98	Antecedents (restructuring the physical and social environments; adding objects to the environment)

	99	Antecedents (restructuring the physical and social environments; adding objects to the environment)
	102	Goals and Planning Antecedents (restructuring the social environment; adding objects to the environment)
	106	Antecedents (restructuring the social environment)
	111	Shaping knowledge Antecedents (restructuring the social environment)
	113	Shaping knowledge Feedback and monitoring
Care Coordination (n=5)	36	Shaping knowledge Antecedents (adding objects to the environment)
	38	Shaping knowledge Antecedents (adding objects to the environment) Feedback and monitoring Natural consequences Goals and planning
	39	Shaping knowledge Antecedents (adding objects to the environment) Natural consequences Goals and planning
	41	Antecedents (adding objects to the environment) Regulation
	55	Shaping knowledge Identity
Effective Treatment (n=5)	68	Shaping knowledge Feedback and monitoring Repetition and Substitution Regulation
	81	Antecedents (restructuring the social environment; adding objects to the environment) Goals and planning Repetition and substitution Regulation
	87	Antecedents (adding objects to the environment) Feedback and monitoring Shaping knowledge
	104	Shaping knowledge Antecedents (restructuring the social environment; adding objects to the environment)
	107	Antecedents (restructuring the social environment) Social support Regulation

* Studies that included some information technology used by patients and/or families.

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3 Overall, the use of antecedents was the most frequently identified category of BCT (n=76, 87.3
4
5 %). This category includes: restructuring the physical environment; restructuring the social environment;
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7 avoidance/reducing exposure to cues for the behavior; distraction; adding objects to the environment
8
9 and body changes (e.g. strength training) .¹⁹ Antecedents can be used to “set the stage” for desired
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11 responses. Because of the frequency of identification of the category of antecedents, this category of
12
13 BCT was further coded into the specific techniques employed. Adding objects to the environment was
14
15 identified as an antecedent in a total of 48 (55.2%) studies. Examples of adding objects to promote
16
17 patient participation in care included the use of instructional videos e.g.^{60, 97} and introduction of
18
19 technologies such as tablets to share information. ³¹ Fifteen (17.2%) of these studies simultaneously
20
21 added objects in conjunction with restructuring the social environment. This is illustrated by Dykes et
22
23 al.’s⁵³ multifaceted intervention involving a patient-centred care and engagement program and web-
24
25 based technology, including a safety checklist and a messaging platform used by patients and care
26
27 partners to view health information, participate in their care plan and communicate with care providers.
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33 Those studies that changed the social environment (n=41, 47.1%) to facilitate patient
34
35 participation in care were classified as having employed the BCT of restructuring the social environment
36
37 [BCT]. Following the BCT coding rules of Preece et al.²⁰, we included in this category studies which
38
39 described interventions in which someone (patients, family member or provider) new took on care,
40
41 someone was added to take on new care responsibilities or someone was added to the team or care
42
43 was shifted outside the team. An example of changes made to the social environment was the adoption
44
45 of new model of care providing flexible family visiting, supporting carer involvement and improving
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47 partnerships between carers and the health care team. ⁵⁷
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51 Five studies (5.7%) were identified as making simultaneous changes to both the social and
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53 physical environments. An instance of changing both the social and physical environment was reported
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55 by Rise et al.⁹⁸, who established a new patient education center as one component of an intervention,
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3 along with appointing staff who could be contacted by families. No studies were identified as
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5 restructuring only the physical environment.
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8 Shaping knowledge was identified as a BCT in 33 studies (37.9%). This BCT is illustrated in the
9
10 study by Langer et al.⁷⁸ in which clinicians were brought together with patients and families in a
11
12 collaborative learning experience focused on developing patient-centred medical error disclosure
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14 communication skills. A second example of shaping knowledge was the use of the PINK (Participate; Be
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16 informed; Notice and be alert; Know what you can do) video⁴⁴ with the specific goal of educating
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18 patients in the prevention of medical errors.
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22 Feedback and monitoring was identified in 20 studies (23.0%). An example is Coleman et al.'s³⁸
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24 Care Transition program, in which patients monitored and responded to changes in their health
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26 conditions as a component of the intervention. Goals and planning were coded in 19 studies (21.8%). An
27
28 example of goals and planning involved goal setting meetings between the patient, family and
29
30 multidisciplinary team [43]. Other categories of BCTs identified in the studies included: social support
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32 (n=7, 8.0%); repetition and substitution (n=5, 5.7%); regulation (n=4; 4.6%); natural consequences (n=3,
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34 3.4%); and comparison of behavior (n=2, 2.3%). The BCTs of association, identity and scheduled
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36 consequences were identified in one study each. Categories of BCT not identified in any of the included
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38 studies were reward and threat, self-belief and covert learning.
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43 In the majority of studies (n=69, 79.3%), the use of multiple categories of BCT as part of the
44
45 capacity-building intervention could be identified. In studies where only a single BCT was identified,
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47 restructuring the social environment^{50, 71, 74, 84, 89, 94, 97, 100, 106, 108} occurred most frequently (n=10),
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49 although adding objects to the environment^{31, 37, 51, 54, 58, 61}, and goals and planning^{46, 49} were also
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51 employed as BCTs.
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55 **4.0 Discussion and Conclusion**

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3 This scoping review has identified seven aspects of care in which efforts to build capacity of
4 hospitalized patients to participate in care were reported: patient safety; care coordination; effective
5 treatment; bedside nursing hand-overs; communication between patients and providers; inpatient care
6 planning; and the overall care environment. Both large-scale (hospital-wide) and population- and unit-
7 specific interventions were reported. Descriptions of these interventions in the included studies
8 provided sufficient detail to allow for classification of the key BCTs utilized within each intervention. The
9 use of antecedents (e.g. adding objects to the environment or restructuring the social and/or physical
10 environment) was the most frequently identified BCT category across all included studies. In 60 per cent
11 of the studies, multiple BCTs could be identified.
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24 In keeping with the nature of a scoping review, the articles included in this scoping review were
25 heterogeneous in terms of the aspect of care addressed, aims and methodological rigor, limiting our
26 ability to draw conclusions about the effectiveness of the interventions. Quality appraisal was not
27 undertaken. Specific details of interventions were not always provided in the publications and it is
28 possible that some BCTs used could not be accurately identified by the three reviewers who classified
29 and achieved consensus on the BCTs identified. While our search strategy was limited to MEDLINE,
30 Embase and CINAHL, it would be helpful to consider the inclusion of additional databases in future
31 reviews. As research addressing patient participation in care becomes increasingly more sophisticated,
32 future reviews may limit the review to specific aspects of care such as safety for defined groups of
33 patients.
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47 Reviews are increasingly seeking to identify the BCTs used in a range of interventions ^{e.g., 116-118} in
48 order to better understand the content of interventions and the underlying reasons for the outcomes
49 associated with interventions. Adding objects to the environment was identified as the most frequently
50 used in BCT in this scoping review, in keeping with the findings of Presseau et al. ²⁰. Depending on the
51 nature of the publication and the intervention, more detailed descriptions of some interventions were
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3 available for some studies compared to others. Attempts to build capacity for patients to participate in
4 care are, at their core, social in nature, and particular care should be taken to describe how the social
5 environment facilitates performance of the desired behavior or creates barriers to unwanted behaviors,
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7 such as excluding patients or families from participation.
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13 Interventions aimed at building the capacity of hospitalized patients to participate more fully in
14 care require the use of complex interventions, especially as patient behavior cannot change
15 independently of provider behavior and health care system attributes. Genuine engagement of patients
16 in care will require a re-alignment of long-standing power imbalances between patients, providers and
17 the health care system, resulting in significant changes in behavior at many levels.¹¹⁹ The participation
18 of a patient representative on this team examining the issue of patient participation proved to be
19 extremely helpful. This individual participated in all aspects of this review, from defining the research
20 question, screening and selection of included studies and data extraction. He provided key insights into
21 the interpretation of the results from the perspective of an end user of the health care system. The
22 recent GRIPP2 reporting checklist on improving the reporting of patient and public involvement in
23 research²⁶ provides important guidance on this issue.
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38 The rapidly evolving interest in developing interventions promoting the participation of
39 hospitalized patients in care was demonstrated by the additional 660 articles that were identified in an
40 eight month period when the search was updated. Given the growing corpus of research, this review
41 provides an important synthesis of what has been reported to build the capacity of hospitalized patients
42 to participate in care. This review aimed also to classify the “active ingredients” underpinning the
43 interventions by using the BCT Taxonomy.¹⁹ The findings generated through this synthesis will provide
44 an evidentiary basis for the development of, and future research related to, tailored approaches to
45 building patient capacity to participate in care.
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15
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21
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23
24 studies and contributed to the interpretation of findings. DG, MM and LN extracted the data. DG drafted
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26 and all authors critically reviewed and approved the manuscript.
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33 Data sharing statement: No additional data are available.
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38 39 References

- 40
41 1. Groene O. Patient-centredness and quality improvement efforts in hospitals: rationale, measurement,
42
43 implementation. *Int J Qual Health Care* 2011;23:531-537.
44
45
46 2. Lombarts MJ, Rupp I, Vallejo P, Sunol R, Klazinga NS. Application of quality improvement strategies in
47
48 389 European hospitals: results of the MARQUIS Project. *BMJ Qual Saf* 2008;18(Suppl1):i28-i37.
49
50
51 3. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for
52
53 understanding the elements and developing interventions and policies. *Health Aff* 2013;32(2):223-231.
54
55
56 4. Clancy CM. Patient engagement in health care. *Health Serv Res* 2011;46:389-393.
57
58
59
60

- 1
2
3 5. World Health Organization. Patient Engagement: Technical Series on Safer Primary Care 2016.
4
5 Available at [http://apps.who.int/iris/bitstream/handle/10665/252269/9789241511629-](http://apps.who.int/iris/bitstream/handle/10665/252269/9789241511629-eng.pdf;jsessionid=2D38D96403E594B7509C1F6079358A6A?sequence=1)
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7 [eng.pdf;jsessionid=2D38D96403E594B7509C1F6079358A6A?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/252269/9789241511629-eng.pdf;jsessionid=2D38D96403E594B7509C1F6079358A6A?sequence=1).
8
9
- 10 6. Hibbard JH, Mahoney ER, Stock R et al. Do increases in patient activation result in improved self
11 management behaviors? Health Serv Res 2007;42:1443-63.
12
13
- 14 7. Mosen DM, Schmittiel J, Hibbard et al. Is patient activation associated with outcomes of care for
15 adults with chronic conditions? J Ambul Care Manage 2007;30:21-9.
16
17
- 18 8. Weingart SN, Zhu J, Chiapetta L et al. Hospitalized patient participation and its impact on quality of
19 care and patient safety. Int J Qual Health Care 2011;23:269-77.
20
21
22
- 23 9. Epstein RM, Franks P, Shields CG et al. Patient-centred communication and diagnostic testing. Ann
24 Fam Med 2005;3:415-21.
25
26
- 27 10. Bertakis KD, Azari R. Patient-centred care is associated with decreased health care utilization. J Am
28 Board Fam Med 2011;24:229-39.
29
30
- 31 11. Charmel P, Frampton S. Building the business case for patient-centred care. Healthc Financ Manage
32 2008;62;80-5.
33
34
35
- 36 12. Aronson PL, Yau J, Helfaer MA et al. Impact of family presence during pediatric intensive care rounds
37 on the family and medical team Pediatrics 2009;24:1119-25.
38
39
40
- 41 13. Balik B, Conway J, Zipperer L, Watson J. Achieving an exceptional patients and family experience of
42 inpatient hospital care. IHI Innovation Series white paper. Cambridge, MASS: Institute for Healthcare
43 Improvement, 2011. Elements of hospital-based patient- and family-centred care
44
45
46
- 47 14. Gausvik C, Lautar A, Miller L, et al. Structured nursing communication on interdisciplinary acute care
48 teams improves perceptions of safety, efficiency, understanding of care plans and team work as well as
49 job satisfaction. J Multidisc Healthcare 2015;8:337.
50
51
52
53
54
55
56
57

- 1
2
3 15. Batalden M, Batalden P, Margolis P, Armstrong G, Opari-Arrigan L, Hartung, H. Coproduction of
4 healthcare service. *BMJ Qual Saf* 2016; 25: 509-17. doi: 10.1136/bmjqs-2015-004315.
5
6
7 16. Gagliardi AR, Legare F, Brouwers MC, Webster F, Badley E, Straus S. Patient-mediated knowledge
8 translation (PKT) interventions for clinical encounters: a systematic review. *Implem Sci* 2016;11:26.17.
9
10
11 17. Herrin J, Harris KG, Kenward K, Hines S, Joshi MS, Frosch DL. Patient and family engagement: a
12 survey of US hospitals. *BMJ Qual Saf* 2015;0: 1-8.
13
14
15 18. Agency for Healthcare Research and Quality. 2015 National healthcare quality and disparities report
16 and 5th anniversary update on the National Quality Strategy: Priorities of the National Quality Strategy.
17 Available at <https://www.ahrq.gov/research/findings/nhqdr/nhqdr15/priorities.html>.
18
19
20 19. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W et al. The Behavior Change
21 Technique Taxonomy (v1) of 93 hierarchically clustered techniques: Building an international consensus
22 for the reporting of behavior change interventions. *Ann Behav Med* 2013;46:81-92.
23
24
25 20. National Institute for Health and Care Excellence (NICE). Behaviour change: individual approaches.
26 <https://www.nice.org.uk/guidance/ph49/chapter/7-glossary>.
27
28
29 21. Presseau J, Ivers NM, Newham JJ, Knittle K, Danko KJ, Grimshaw JM. Using a behavior change
30 techniques taxonomy to identify active ingredients within trials of implementation interventions for
31 diabetes care. *Implem Sci* 2015;10:55
32
33
34 22. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *Int J Soc Res Meth*
35 2005;8:19-32.
36
37
38 23. Colquhoun HL, Levac D, O'Brien KK, Straus S, Tricco AC, Perrier, Kastner M, Moher D. Scoping
39 reviews: time for clarity in definition, methods and reporting. *J Clin Epidemiol* 2014;67:1291-4.
40
41
42 24. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology, *Implement. Sci.* 5
43 (2010) 69.
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 25. Daudt HML, van Mossel C, Scott SJ. Enhancing the scoping study methodology: a large, inter-
4 professional team's experience with Arksey and O'Malley's framework. *BMC Med. Res. Methodol.* 13
5 (2013) 48.
6
7
8
9
10 25. Tricco AC, Antony J, Zarin W, Strigler L, Ghassemi M, Ivory J et al. A scoping review of rapid review
11 methods. *BMC Med* 2015;13:224.
12
13
14 26. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. GRIPP2 reporting checklists:
15 tools to improve reporting of patient and public involvement in research. *BMJ* 2017;358:j3453.
16
17
18 27. Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia. Available
19 at <http://www.covidence.org>.
20
21
22
23 28. Anthony R, Miranda F, Mawji Z, Cerimele R, Davis R, Lawrence S. John M. Eisenberg Patient Safety
24 Awards. The LVHNN patient safety video: patients as partners in safe care delivery. *Joint Comm J Qual*
25 *Saf* 2003;29:640-645.
26
27
28
29 29. Ayana M, Pound P, Ebrahim S. The views of therapists on the use of a patient-held record in the care
30 of stroke patients, *Clin Rehab* 1998;12:328-337.
31
32
33 30. Baird SK, Turbin LB. Condition Concern: an innovative response system for enhancing hospitalized
34 patient care and safety. *J Nurs Care Qual* 2011;26(3):199-207.
35
36
37 31. Baysari MT, Adams K, Lehnbohm EC, Westbrook JI, Day RO. iPad use at the bedside: a tool for
38 engaging patients in care processes during ward rounds? *Int Med J* 2014;44(10):987-990.
39
40
41 32. Berger JL. Incorporation of the tidal model into the interdisciplinary plan of care – a program quality
42 improvement project. *J Psychiatr Men Health Nurs* 2006;12:464-467.
43
44
45 33. Black P, Boore HRP, Parahoo K. The effect of nurse-facilitated family participation in the
46 psychological care of the critically ill patient. *J Adv Nurs* 2011; 76(5):1091-1101.
47
48
49 34. Boltz M, Chippendale T, Resnick B, Galvin JE. Testing family-centred, function-focused care in
50 hospitalized persons with dementia. *Neurodegener Dis Manage* 2015;5(3):203-215.
51
52
53 35. Bradley S, Mott S. Adopting a patient-centred approach: an investigation into the introduction of
54 bedside hand-over to three rural hospitals. *J Clin Nurs* 2014;23:1927-1936.
55
56
57
58
59
60

- 1
2
3 36. Bull MJ, Hansen HE, Gross CR. A professional-patient partnership model of discharge planning with
4 elders hospitalized with heart failure. *Appl Nurs Res* 2000;13:19-28.
5
6
7 37. Buning AW, Klopotoska JE, Duyvendak M, Engelen LJP, Arts J. Patient empowerment through the
8 provision of a mobile application for medication reconciliation: a proof of concept study. *BMC*
9 *Innovations* 2016;2:152-157.
10
11
12 38. Coleman EA, Parry C, Chalmers S, Min SJ. The care transitions intervention: results of a randomized
13 controlled trial. *Arch Int Med* 2006;166:1822-9.
14
15
16 39. Coleman EA, Smith JD, Parry C, Chalmers S, Min SJ. Preparing patients and caregivers to participate
17 in care delivered across settings: The care transitions intervention. *J Am Ger Soc* 2004;52:1817-1825.
18
19
20
21 40. Cook DJ, Manning DM, Holland DE, Prinsen SK, Rudzik SD, Roger VL, Deschamps C. Patient
22 engagement and self-reported outcomes in surgical recovery: effectiveness of an e-health platform. *J*
23 *Am Coll Surg* 2013;217:648-655.
24
25
26 41. Cordasco KM, Asch SM, Bell DS, Guterman JJ, Gross-Schulman S, Ramer L et al. A low-literacy
27 education tool for safety-net hospital patients. *Am J Prev Med* 2009;37:S209-S216.
28
29
30
31 42. Dalal AK, Dykes PC, Collins S, Lehmann LS, Ohashi Km Rozenblum R et al. A web based, patient-
32 centred toolkit to engage patients and caregivers in the acute-care setting: a preliminary evaluation. *J*
33 *Am Med Inform Assoc* 2016;23:80-87.
34
35
36 43. Dalton C, Farrell R, De Souza A, Wujanto E, McKenna-Slade A, Thompson S et al. Patients inclusion in
37 goal setting during early inpatient rehabilitation after acquired brain injury. *Clin Rehab* 2012;26:165-173.
38
39
40 44. Davis RE, Pinto A, Sevdalis N, Vincent C, Massey R, Darzi A. Patients' and professionals' attitudes
41 towards the PINK patient safety video. *J Eval Clin Pract* 2012;18:848-853
42
43
44 45. Davis RE, Sevdalis N, Pinto A, Darzi A, Vincent CA. Patients' attitudes towards patient involvement in
45 safety interventions: results of two exploratory studies. *Health Exp* 2013;16:163-176.
46
47
48 [46] D'Cruz K, Unsworth C, Roberts K, Morarty J, Turner-Stokes L, Wellington-Boyd A et al. Engaging
49 patients with moderate to severe acquired brain injury in goal setting. *Int J Ther Rehab* 2016;23:20-31.
50
51
52 47. Dev R, Coulson L, Del Fabbro E, Palla SL, Yennurajalingam S, Rhondali W, Bruera E. A prospective
53 study of family conferences: Effects of patient presence on emotional expression and end-of-life
54 discussions. *J Pain Sympt Manag* 2013;46:536-545.
55
56
57

- 1
2
3 48. Dijkstra R, Braspenning J, Grol R. Empowering patients: how to implement a diabetes passport in
4 hospital care. *Pat Ed Couns* 2002;47:173-177.
5
6
7 49. Donnelly SM, Carter-Anad J, Cahill S, Gilligan R, Mehigan B, O'Neill D. Multiprofessional views on
8 older patients' participating in care planning meetings in a hospital context. *Practice Soc Work Act*
9 2013;25;121-138.
10
11
12 50. Doyle CJ, Post H, Burney RE, Maino J, Keefe M, Rhee KJ et al. Family participation during
13 resuscitation: an option. *Ann Emerg Med* 1987;16:673-675.
14
15
16 51. M. Duckworth, E. Leung, T. Fuller, J. Espares, B. Couture, F. Chang, A.C. Businger, S. Collings, A. Dalal,
17 A. Fladger, J.L. Schnipper, K.O. Schnook, D.W. Bates, P.C. Dykes. Nurse, patient and care partner
18 perceptions of a personalized safety plan screensaver. *J. Gerontol. Nurs* (2017) 43:15-22.
19
20
21 52. Duncan C. An exploratory study of patients' feeling about asking healthcare professionals to wash
22 their hands. *J Ren Care* 2007;33:30-34.
23
24
25 53. Dykes PC, Rozenblum R, Dalal A, Massaro A, Chang F, Clements M, et al. Prospective evaluation of a
26 multifaceted intervention to improve outcomes in intensive care: The Promoting Respect and Ongoing
27 Safety through Patient Engagement Community and Technology Study. *Crit Care Med* 2017; 5:e806-
28 e813.
29
30
31 54. Dykes PC, Stade D, Chang F, Dalal A, Getty G, Kandala R et al. Participatory design and development
32 of a patient-centred toolkit to engage hospitalized patients and their care partners in their plan of care.
33 *AMIA Symposium* 2014:486-495.
34
35
36 55. Dystad DN, Storm M. Interprofessional simulation to improve patient participation in transitional
37 care. *Scand J Car Sci* 2017;31:273-284.
38
39
40 56. Ellegaard T, Bliksted V, Lomborg K, Mehlsen M. Use of patient-controlled psychiatric hospital
41 admissions: patients' perspective. *Nord J Psychiatry* 2017;71:370-77.
42
43
44 57. Ewart L, Moore J, Gibbs C, Crozier K. Patient- and family-centred care on an acute adult cardiac ward.
45 *Brit J Nurs* 2013;23:213-218.
46
47
48 58. Fredericks JE, Bunting RF. Implementation of a patient-friendly medication schedule to improve
49 patient safety within a healthcare system. *J Healthcare Risk Manag* 2010;29:22-27.
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 59. Furness ND, Bradford OJ, Paterson MP. Tables in trauma: mobile computing platforms to improve
4 patients understanding and experience. *Orthoped* 2013;36:205-208.
5
6
7 60. Gillespie BM, Chaboyer W, Sykes M, O'Brien J, Brandis S. Development and pilot-testing of a patient-
8 participatory pressure ulcer prevention care bundle. *J Nurs Care Qual* 2014;29:74-82.
9
10
11 61. Gill SD, Redden-Hoare J, Dunning TL, Hughes AJ, Dolley PJ. Health services should collect feedback
12 from inpatients at the point of service: opinions from patients and staff in acute and subacute facilities.
13 *Int J Qual Healthc* 2015;27:507-512.
14
15
16 62. Gillis C, Gill M, Marlett N, Mackean G, Germann K, Gilmour K et al. Patients as partners in Enhanced
17 Recovery after Surgery: a qualitative patient-led study. *BMJ Open* 2017;7;no pagination.
18
19
20 63. Greenhouse PK, Kuzminsky B, Martin SC, Merryman T. Emergency calling a condition h(elp): one
21 facility gives patients and families the ability to summon a rapid response team. *Am J Nurs* 2006;106:63-
22 66.
23
24
25 64. Greysen SR, Khanna RR, Jacolbia R, Lee HM, Auerbach AD. Tablet computers for hospitalized
26 patients: a pilot study to improve patient engagement. *J Hosp Med* 2014;9:396-399.
27
28
29 65. Grieco AJ, Garnett SA, Glassman KS, Valoon PL, McClure ML. New York University Medical Center's
30 Cooperative Care Unit: Patient education and family participation during hospitalization – the first ten
31 years. *Pat Ed Couns* 1990;15:3-15.
32
33
34 66. Hamann J, Mendel R, Meier A, Asani F, Pausch E, et al. "How to Speak to your Psychiatrist": Shared
35 decision-making training for patients with schizophrenia. *Psych Serv* 2011;62:1218-1221.
36
37
38 67. Hill AM, McPhail SM, Francis-Cload-J, Waldron N, Etherton-Ber C, Flicker L, et al. Educators'
39 perspectives about how older patients can engage in a falls prevention education programme: a
40 qualitative process outcome. *BMJ Open* 2015;5(12)(no pagination)
41
42
43 68. Hirano Y, Maeshima S, Osawa, Nishio D, Takeda K, Baba M et al. The effect of voluntary training with
44 family participation on early home discharge in patients with severe stroke at a convalescent
45 rehabilitation hospital. *Eur Neurol* 2012;68:221-228..
46
47
48 69. Huffines M, Johnson KL, Naranjo LS, Lissauer ME, Fishel MA, D'Angelo SM. Participation in decision-
49 making in an intensive care unit. *Crit Care Nurs* 2013;33:56-69.
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 70. Ivarsson B, Larsson S, Luhrs C, Sjoberg T. extended written pre-operative information about possible
4 complications at cardiac surgery – do patients want to know? *Eur J Cardio-Thorac Surg* 2005;28:407-14.
5
6
7 71. Jacobowski NL, Girard TD, Mulder JA, Ely EW. Communication in critical care: family rounds in the
8 intensive care units. *Am J Crit Care* 2010;19:421-430.
9
10
11 72. Jangland E, Carlsson M, Lundgren E, Gunningberg L. The impact of an intervention to improve
12 patient participation in a surgical care unit: a quasi-experimental study. *Int J Nurs Stud* 2012;49:528-538.
13
14
15 73. Jangland E, Gunningberg L. Improving patient participation in a challenging context: a 2-year
16 evaluation study of an implementation project. *J Nurs Manag* 2017;25:266-275.
17
18
19 74. Jeffs L, Beswick S, Acott A, Simpson E, Cardoso R, Campbell H et al., Patients' views on bedside
20 handover. *J Nurs Care Qual* 2014;29:149-154.
21
22
23 75. Kutty S, Weil S. "Your health care – be involved": the evaluation of a provincial safety tips initiative.
24 *Healthc Quar* 2006;9:102-107.
25
26
27 76. Laitinen-Junkkari P, Merilainen P, Sinkkonen S. Informal caregivers' participation in elderly-patient
28 care: an interrupted time series study. *Int J Nurs Pract* 2001;7:199-213.
29
30
31 77. Lakeman R. Practice standards to improve the quality of family and carer participation in adult
32 mental health: an overview and evaluation. *Int J Ment Health Nurs* 2008;17:44-56.
33
34
35 78. Langer T, Martinez W, Browning D, Varrin P, Sarnoff Lee B, Bell SK. Patients as teachers in patient
36 safety: a new interprofessional educational model for collaborative learning about medical error
37 disclosure and prevention. *J Gen Int Med* 2015;30:S504.
38
39
40
41 79. Lankarani-Fard A, Knapp H, Lorenz KA, Golden JF, Taylor A, Feld JE, et al. Feasibility of discussing end-
42 of-life goals with inpatients using a structured, conversational approach: the go-wish care game. *J Pain*
43 *Sympt Manag* 2010;39:637-43.
44
45
46
47 80. Lawton R, O'Hara JK, Sheard L, Armitage G, Cocks K, Buckley H et al. Can patient involvement
48 improve patient safety? A cluster randomized control trial of the Patient Reporting and Action for a Safe
49 Environment (PRASE) intervention. *BMJ Qual Saf* 2017;26:622-631.
50
51
52
53 81. Lean M, Leavey G, Killaspy H, Green N, Harrison I, Cook S et al. Barriers to the sustainability of an
54 interventions designed to improve patient engagement within NHS mental health rehabilitation units: a
55 qualitative study nested within a randomized controlled trail. *BMC Psychiat* 2015; 15: (no pagination)
56
57

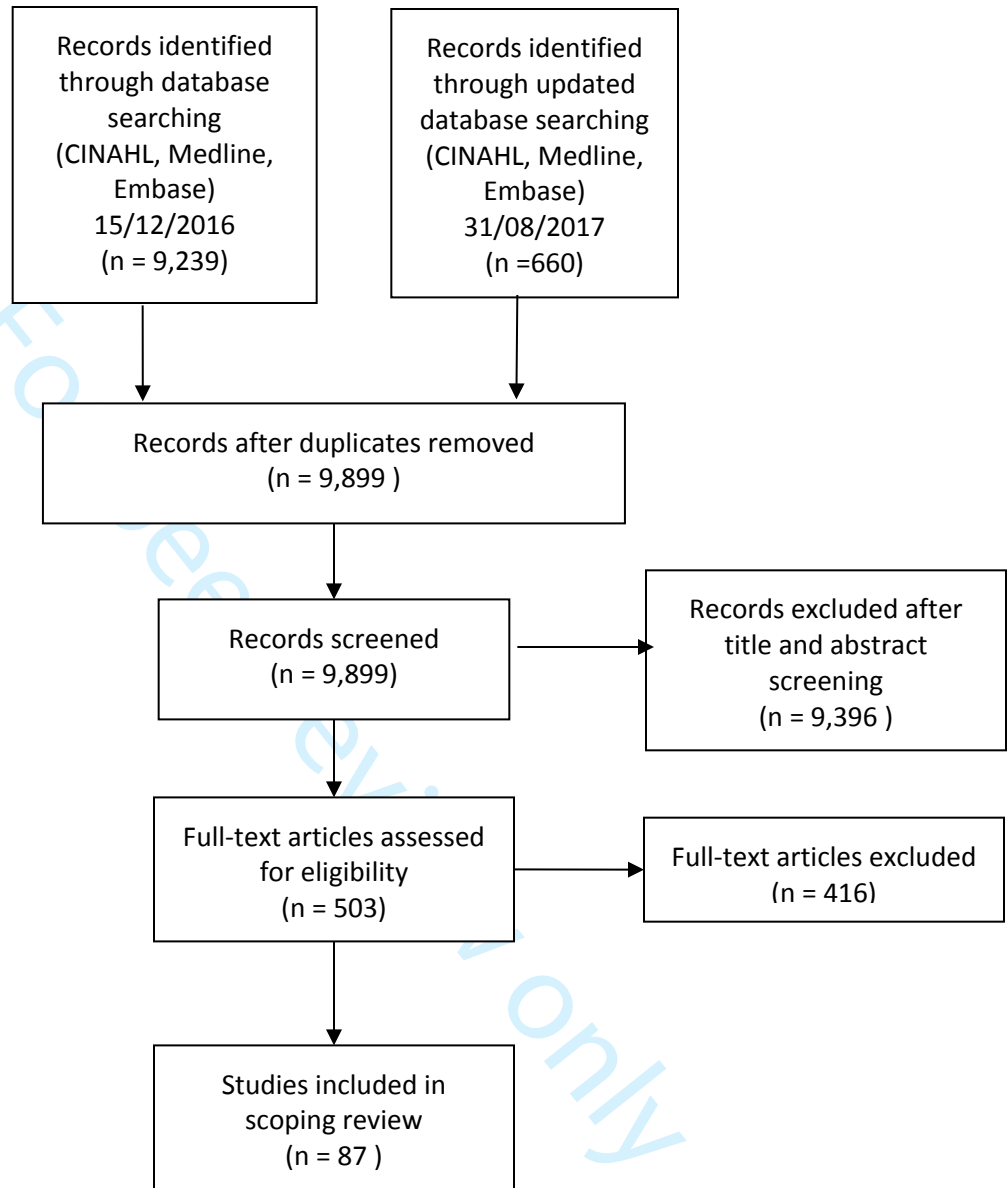
- 1
2
3 82. Lent V, Eckstein EC, Cameron AS, Budavich R, Eckstein BC, Donskey CJ. Evaluation of patient
4 participation in a patient empowerment initiative to improve hand hygiene practices in a Veterans
5 Affairs medical center. *Am J Inf Contr* 2009;37:117-120.
6
7
8
9 83. Leske JS, McAndrew NS, Brasel KJ, Feetham S. Family presence during resuscitation after trauma. *J*
10 *Trauma Nurse* 2017;24;85-96.
11
12
13 84. Lindberg E, Persson E, Horberg U, Ekeburgh M. Older patients' participation in team meetings – a
14 phenomenological study from the nurses' perspective. *Int J Qual Stud Health Well-being*
15 2013;8;10.3402/qhw.v8i0.21908
16
17
18 85. Livingston JD, Nijdam-Jones A, Lapsley S, Calderwood C, Brink J. Supporting recovery by improving
19 patient engagement in a forensic mental health hospital: results from a demonstration project. *J Am*
20 *Psychiatr Nurs Assoc* 2013;19:132-145.
21
22
23
24 86. Louch G, O'Hara J, Mohammed MA. A qualitative formative evaluation of a patient-centred patient
25 safety intervention delivered in collaboration with hospital volunteers. *Health Expect* 2017;15:15.
26
27
28 87. Martinez-Velilla N, Guerrues-irisarri M, Ibanez-Beroia B, Gil-Cabanas J, Richarte-Carcia A, Idoate-
29 Saralegui F et al. An exercise program with patients' involvement and family support can modify the
30 cognitive and affective trajectory of acutely hospitalized older medical patients: a pilot study. *Aging Clin*
31 *Exp Res* 2016;28:483-490.
32
33
34
35 88. McGuckin M, Waterman R, Storr J, Bowler ICJW, Ashby M, Topley K et al. Evaluation of a patient-
36 empowering hand hygiene program in the UK *J Hosp Inf* 2001;48:222-227.
37
38
39 89. McMurray A, Chaboyer W, Wallis M, Johnson J, Gehrke T. Patients perspectives of bedside nursing
40 handover. *Collegian* 2011;18:19-26.
41
42
43
44 90. Nyborg I, Kvigne K, Danbolt LJ, Kirkevold M. Ambiguous participation in older hospitalized patients:
45 gaining influence through active and passive approaches – a qualitative study. *BMC Nurs*;15:50.
46
47
48 91. Odell M, Gerber K, Gager M. Call 4 concern: patient and relative activated critical care outreach. *Br J*
49 *Nurs* 2010;19:1390-1395.
50
51
52 92. O'Leary KJ, Lohman ME, Culver E, Killarney A, Smith GR, Liebovitz DM. The effect of tablet computers
53 with a mobile patient portal application on hospitalized patients' knowledge and activation. *J Am Med*
54 *Inform Assoc* 2016;23:159-165.
55
56
57

- 1
2
3 93. Olso TM, Gudde CB, Moljord IEO, Evensen GH, Antonsen DO et al. More than just a bed: mental
4 health service users' experiences of self-referral admission. *Int j Ment Health Sys* 2016;10: (no
5 pagination).
6
7
8
9 94. Paradis E, Leslie M, Gropper MA. Interprofessional rhetoric and operational realities: an
10 ethnographic study of rounds in four intensive care units. *Adv Health Sci Educ* 2016;21:735-48.
11
12
13 95. Pegg PO, Auerbach SM, Seel RT, Buenaver LF, Keisler DJ, Plybon LE. The impact of patient-centred
14 information on patients' treatment satisfaction and outcomes in traumatic brain injury rehabilitation.
15 *Rehab Psychol* 2005;50:366-374.
16
17
18 96. Pinto A, Vincent C, Darzi A, Davis R. A qualitative exploration of patients' attitudes towards the
19 "Participate Inform Notice Know" (PINK) patient safety video *Int J Qual Health Care* 2013; 25:29-34.
20
21
22 97. Pomey MP, Ghadiri DP, Karazivan P, Fernandez N, Clavel N. Patients as partners: a qualitative study
23 of patients' engagement n their health care. *PLoS ONE* 2015;10: (no pagination) e0122499.
24
25
26 98. Rise MB, Grimstad H, Solbjor M, Steinsbekk A. Effect of an institutional development plan for user
27 participation on professionals' knowledge, practice and attitudes. A controlled study. *BMS Health Serv*
28 *Res* 2011;11:296.
29
30
31 99. Rise MB, Steinsbekk A. Does implementing a development plan for user participation in a mental
32 health hospital change patients' experience? A non-randomized controlled study. *Health Expect*
33 2105;18:809-825.
34
35
36 100. Rotman-Pikielny P, Rabin B, Amoyal S, Mushkat Y, Zissin R, Levy Y. Participation of family members
37 in ward rounds: attitude of medical staff, patients and relatives. *Pat Ed Couns* 2007;65:166-170.
38
39
40 101. Ruland CM. Decision support for patient preference-based care planning: effects on nursing care
41 and patient outcomes. *J Am Med Inform Assoc* 1999;6:304-12.
42
43
44 102. Ruland CM. Clinicians' use of a palm-top based system to elicit patient preferences at the bedside:
45 a feasible technique to improve patient outcomes. *Proc AMIA* 2000;739-43.
46
47
48 103. Sand-Jecklin K, Sherman J. Incorporating bedside report into nursing handoff: evaluation of change
49 in practice. *J Nurs Care Qual* 2013;28:186-194.
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 104. See MTA, Chan WCS, Huggan PJ, Tay YK, Liaw SY. Effectiveness of a patient education intervention
4 in enhancing the self-efficacy of hospitalized patients to recognize and report acute deteriorating
5 conditions. *Pat Ed Coun* 2014;97:122-127.
6
7
8
9 105. Sehgal NL, Green A, Vidyarthi AR, Blegen MA, Wachter RM. Patient whiteboards as a
10 communication tool in the hospital setting: a survey of practices and recommendations. *J Hosp Med*
11 2010;5:234-9.
12
13
14 106. Shulkin D, O'Keefe T, Visoni D, Robinson A, Rooke AS, Neigher W. Eliminating visiting hour
15 restrictions in hospital. *J Healthcare Qual* 2014;26:54-57.
16
17
18 107. Skolasky RL, Maggard AM, Li D, Riley LH, Wegener ST. Health behavior change counseling in surgery
19 for degenerative lumbar stenosis. Part II: Activation mediates the effects of health behavior change
20 counseling on rehabilitation engagement.
21
22
23 108. Stein EG, Furedy RL, Simonton MJ, Neuffer CH. Patient access to medical records on a psychiatric
24 inpatient unit *Am J Psychiatr* 1979;136:327-9.
25
26
27
28 109. Swenne CL, Skytt B. The ward round – patient experiences and barriers to participation. *Scand J Car*
29 *Sci* 2014;28: (8p)
30
31
32 110. Timonen L, Sihvonon M. Patient participation in bedside reporting on surgical wards. *J Clin Nurs*
33 2000;9:542-548.
34
35
36 111. Trummer UF, Mueller UO, Nowak P, Stidl T, Pelikan JM. Does physician-patients communication
37 that aims at empowering patients improve clinical outcome? A case study. *Pat Ed Couns* 2006;61:299-
38 306.
39
40
41
42 112. Turner J, Gardner B, Staples T, Chapman J. Medicines with respect (part two): Implementation and
43 evaluation of a medication management initiative in acute in-patient settings. *Ment Health Nurs*
44 2008;28:12-16.
45
46
47 113. Van Gaal BGI, Schoonhoven L, Mintjes JAJ, Borm GF, Hulscher MEJL, Defloor T et al. Fewer adverse
48 events as a result of the SAFE or SORRY? Programme in hospitals and nursing homes. Part i: primary
49 outcome of a cluster randomized trial. *Int J Nurs Stud* 2011;49:1040-1048.
50
51
52
53 114. Wressle E, Eeg-Olofsson A-M, Marcusson J, Henriksson C. Improved client participation in the
54 rehabilitation process using a client-centred goal formulation structure. *J Rehabil Med* 2002;34:5-11.
55
56
57

- 1
2
3 115. CA Young, Manmathan GP, Ward, JC. Perceptions of goal-setting in a neurological rehabilitation
4 unit: a qualitative study of patients, carers and staff. *J Rehabil Med* 2008;40:190-4.
5
6
7 116. L. Hollywood, D. Surgenor, M. Reicks, L. McGowan, F. Lavelle, M. Spence, M. Raats, A. McCloat, E.
8 Mooney, M. Caraher, M. Dean, Identification of behavior change technique applied in interventions to
9 improve cooking skills and food skills among adults. *Crit. Rev. Food. Sci. Nutr.* 7 (2017) 1-14.
10
11 117. L. Kahwati, M. Viswanathan, Golin C.E., H. Kane, M. Lewis, S. Jacobs S. Identifying configurations of
12 behavior change techniques in effective medication adherence interventions: a qualitative comparative
13 analysis. *System Rev.* 5 (2016) 83.
14
15
16 118. Soltani H, Arden MA, Duxbury AMS, Fair FJ. An analysis of behavior change technique used in a
17 sample of gestational weight management trial. *J Pregnancy* 2016;Article ID 1085916.
18
19
20
21
22 119. Goodridge D, Isinger T, Rotter T. Patient family advisors' perspectives on engagement in health-
23 care quality improvement initiatives: power and partnership. *Health Exp* 2017; 21:379-386.
24
25
26
27
28
29
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Figure 1.



Supplementary File 1: Search Strategy - Comprehensive Medline Strategy

Database(s): Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

Search Strategy:

#	Searches	Results
1	acute care.mp. hospitals/ or exp hospitals, community/ or exp hospitals, general/ or exp hospitals, group practice/ or exp hospitals, high-volume/ or exp hospitals, low-volume/ or exp hospitals,	17713
2	private/ or exp hospitals, public/ or exp hospitals, rural/ or exp hospitals, satellite/ or exp hospitals, teaching/ or exp hospitals, urban/ or secondary care centers/ or tertiary care centers/	197791
3	hospital*.mp.	1356031
4	inpatients/ (in-patient? or inpatient?).mp. [mp=title, abstract, original title, name of substance word,	17400
5	subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	1503794
6	or/1-5	2652901
7	patient participation/	22552
8	caregivers/	29583

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3	9	family/
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19	14	stakeholder? or user?) adj2 (empower* or engage* or participat*).ab. /freq=2
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24	15	stakeholder? or user?) adj2 (empower* or engage* or participat*).ti.
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29		((carer? or caregiver? or client? or consumer? or families or family or patient? or
30	16	stakeholder? or user?) adj involve*).ab. /freq=2
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35	17	stakeholder? or user?) adj involve*).ti.
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For peer review only

Supplementary File 2. Scoping Review Data Extraction Sheet

Primary author/organization:		
Title of article:		
Source of publication (Name of journal or report):		
Year of publication:		
Reviewer initials:		
Country		
Overall Aim and Purpose of the Study		
Focus of Patient Engagement Program		
Describe the Intervention		
Duration of Program		
Theoretical Framework (Identify and describe, if present)		
Study Design (Quantitative)	Case Series	
	Cross-Sectional (Pre- and post)	
	Case-control	
	Retrospective Cohort	
	Prospective Cohort	
	RCT	
	Other	
Study Design (Qualitative)	Basic Interpretive	
	Phenomenological	
	Grounded Theory	
	Ethnographic	
	Case Study	
	Other	
Study Design (Mixed Methods)	QUAL core QUAN core Sequence	
	Instruments Used	

1	Non-Research Document	Describe type	
2	Type of Hospital	Teaching	
3		Community	
4		Rehabilitation	
5		Psychiatric/Mental Health	
6		Other	
7	Type of Unit		
8	Participants	Number of participants	
9		Type of Participants	Patient Family Member Care Provider Other
10		Medical diagnoses	
11		Age range	
12		Sex (%)	
13		Inclusion criteria	
14		Exclusion criteria	
15	Results	Patient outcomes	
16		Health care provider outcomes	
17		Health system & effectiveness outcomes	
18		Funder outcomes	
19	Comments		

Supplementary File 3. Summary of Included Articles

Citation	Country	System Improvement	Description of Intervention	Study Design, Participants	Findings	BCT
28	US	Patient Safety	Patient video addressing: treatment plan, med safety, falls, surgical site identification, hand-washing and discharge planning.	Survey of 217 patients	Increased comfort in talking to providers about concerns Self-rated knowledge of patient safety improved	Shaping knowledge Antecedents (adding objects to the environment)
29	UK	PFCC: Bedside Nursing Handovers	Patient-held booklet for staff to record information on management. Aim was to facilitate communication and involve patients in rehabilitation care.	Six focus groups of therapists (n=25) Content analysis	Supportive, but questioned feasibility for both patients and staff. Ownership does not guarantee confidence needed to encourage dialogue. Differences in philosophies of care between therapists.	Shaping knowledge Antecedents (adding objects to the environment)
30	US	Patient Safety	Method to report unattended care concerns (call hospital emergency alert system). Aim to provide a practical safety net. Policies, education, audit tool signage for program.	Data on concern reports gathered over 6 months.	69 calls (3 x greater than a similar program). Key issues: plan of care; pain management; coordination of care; response to call light; other; not valid concern and dissatisfied with staff.	Antecedents (Restructuring the physical and social environment; adding objects to the environment)
31	Hospital AU	PFCC: Communication	iPad to share information with patient during ward rounds	10 senior doctors shadowed on rounds with 525	iPads were not used to share information. Patients did not believe	Antecedents (Adding objects to the environment)

				patients over 77 hours. 7 doctors interviewed and 180 patients completed survey.	iPads impacted on engagement.	
32	CAN	PFCC: Care environments	Tidal model focuses on engaging person and client-centred care in psychiatry.	46 patients and 17 staff completed short questionnaires	IPC associated with client and caregiver satisfaction (no validated instruments used)	Goals and Planning Antecedents (Restructuring the social environment)
33	UK	PFCC: Communication	Family education on delirium and psychological care via booklet – nurses promote family access to patient and encouraged interaction in ICU.	Comparative time series of 170 critically ill patients and families – 83 controls, 87 intervention	No reduction in delirium, but patients demonstrated better psychological recovery and well-being at 4, 8, and 12 weeks	Shaping knowledge Social Support
34	US	PFCC: Care environments	Create enabling environment that promoted medical patient engagement in functional recovery. Environmental and Policy Evaluation; Staff education; Ongoing training and motivation of nursing staff; FamCare. Individualized goals and mentoring.	Comparative repeated measures design; 44 dyads on intervention units and 42 dyads on control	Intervention group demonstrated better ADL and walking, less severity/duration of delirium and readmission, no significant difference in gait/balance. Families showed increased preparedness for caregiving and less anxiety but no differences in depression, strain or mutuality.	Goals and planning Feedback and monitoring Antecedents (Restructuring the physical and social environments)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20	35	AU	PFCC: Bedside nursing hand-over	Nurse-to-nurse bedside handover in rural hospitals.	Mixed methods, pretest, post- test approach using quasi- experimental and ethnographic elements. Ethnographic interviewing. Staff perceptions on scale and by interview. 9 inpatients and 48 nursing staff.	Patients preferred bedside hand-over (know who is caring for them, social aspects and inclusion). Staff believed patient involvement had increased.	Antecedents Restructuring the physical and social environments Scheduled consequences
21 22 23 24 25 26 27 28 29 30 31	36	US	Care Coordination	Educational program for nurses and social workers; cardiac patients and caregivers completed discharge planning survey and viewed video; given structured questions; given medication list and brochure on accessing community services	Before and after non-equivalent control group design with 158 dyads and 2 month follow- up in two hospitals	Patients felt more prepared to manage care, reported more continuity of information, felt they were in better health, reduced LOS when re- admitted	Shaping knowledge Antecedents (adding objects to the environment)
32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47	37	The Nether- lands	Patient safety	Patient-operated mobile app MyMedication to assist with medication reconciliation. Patients create their own medication lists of the medications they actually use. Barcodes can be scanned and matched	Convenience sample of 17 elective surgery patients. AT admission, medication list in app was compared with	The use of the app shows potential as a tool to improve patient safety and reduce healthcare costs.	Antecedents (adding objects to the environment)

			with database included in the app.	list compiled by a pharmacy practitioner and discrepancies quantified.		
38	US	Care Coordination	Transition coach for medical patients. 4 pillars: assistance with medication self-management; patient-centred record owned and maintained by the patient; timely follow-up with primary or specialty care; list of “red flags” indicative of worsening condition and how to respond to them	Randomized controlled trial with 750 medical patients randomized into intervention and control groups. Primary outcome: rate of non-elective rehospitalization at 30, 90, 180 days post discharge after index hospitalization	Intervention patients had significantly lower re-admission and rates at all intervals and lower hospital costs.	Shaping knowledge Antecedents (adding objects to the environment) Feedback and monitoring Natural consequences Goals and planning
39	US	Care Coordination	Program for medical patients being discharged. 4 pillars: assistance with medication self-management; patient-centred record owned and maintained by the patient; timely follow-up with primary or specialty care; list of “red flags” indicative of worsening condition and how to respond to them	Quasi-experimental design with 158 medical patients receiving intervention and comparison with administrative data for 1,235 controls	Significant decrease in re-hospitalizations for intervention group at 30, 90 and 180 days. Participants receiving the intervention reported high levels of confidence in obtaining essential information for managing their condition, communicating with the health care team	Shaping knowledge Antecedents (adding objects to the environment) Natural consequences Goals and planning

					and understanding their medication regimen.	
40	US	PFCC: Care Planning	Integrate self-assessment and self-reporting using e-health platform (iPad) to deliver personalized care plan while hospitalized. iPad loaded with software designed to support recovery and discharge planning after cardiac surgery.	Survey of 149 patients who completed 1,418 assessments (97.6% completion)	e-Health platform, combined with mobile computing, can deliver customized care with which patients can interact. PROs have predictive value for resource use and outcomes.	Feedback and monitoring (Self-monitoring of behavior) Antecedents (Adding objects to the environment)
41	US	Care Coordination	Developed a prototype low-literacy medication education tool, customizable for each patient, using icons and photos of pills	Interviews of 166 participants two weeks and 85 participants 4 weeks after discharge	Participants who received the intervention self-reported their medication adherence more accurately and demonstrated improved knowledge about the purposes of their medications, but there was no effect on self-reported medication adherence	Antecedents (Adding objects to the environment) Regulation (Conserving mental resources)
42	US	PFCC: Communication	Provided access to iPad to input goals, preferences, concerns; view team goals, problems and schedule of events; access educational content; send messages to care team	Evaluation of usage in 239 patients and caregivers. 18/32 patients completed system usability	Most frequent use was to send messages related to health concerns, needs, preferences or questions. Use of educational content highest for medications	Goals and planning Antecedents (Restructure social environment;

				and satisfaction survey.	and test results and lowest for problems	Adding objects to the environment)
43	UK	PFCC: Care planning	Goal setting meetings with patient, relative as needed and multidisciplinary team	Case-controlled retrospective study of 105 patients comparing the number of goals set between patients admitted before and after goal-setting process introduced.	Significant increase in number of goals set per patient. Proportion of goals achieved similar to pre-intervention	Goals and planning Antecedents (Restructure social environment)
44	UK	Patient Safety	PINK is a 4 minute animated video aimed at helping patients prevent errors by encouraging to : Participate; be Informed; Notice and be alert; and Know what they can do to facilitate their recovery	Within-subjects pre- and post-screening of safety video using questionnaires with 201 patients and 95 health professionals	Post-video patients were more positive about asking doctors and nurses if they had washed their hand and notifying them about issues to do with personal hygiene. No effects on patients notifying staff about not receiving medications or in pain or unwell. Providers were more willing to support patient involvement post-video.	Shaping Knowledge Antecedents (adding objects to the environment)

1 2 3 4 5 6 7 8 9 10 11 12	45	UK	Patient Safety	Safety video (Study 1) and leaflet (Study 2) encouraging participation in safety-related behaviors	Exploratory, pre-post, within-subjects mixed methods design studies with 80 participants in each study	Increased comfort reported in engaging in some, but not all, safety-related behaviors. Patients questioned whether intervention would help reduce medical error.	Shaping knowledge Antecedents (adding objects to the environment)
13 14 15 16 17 18 19 20 21 22 23 24 25 26	46	AU	PFCC: Communication	Goal-setting interviews in rehabilitation	Exploratory, mixed methods study of 22 triads (patients, family and provider)	Provider views dominated the goal setting process. Strategies to promote goal-setting through supporting the unknown experience of injury and hospitalization: build trust; be responsive; open and honest approach.	Goals and planning
27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47	47	US	PFCC: Care planning	Family and team discussion of palliative medical condition, patient and family understanding of treatment option and disease burden, directions of medical care	Survey of 140 family caregivers post-intervention; observational data on emotional expression collected during meetings	Frequent expressions of distress from patients and families. Questions were infrequent, Patient presence significantly associated with increased discussion of goals of care, prognosis and expected symptoms at death, but decreased	Goals and planning Antecedents (Restructure the social environment)

					discussion of medical information.	
48	The Netherlands	PFCC: Communication	Passport describes, records and evaluates medical screening results to achieve treatment goals.	Qualitative (focus groups with 29 patients and 21 providers)	Purpose of passport unclear to patients. Reviews were mixed on ease of use, responsibility for completion and usefulness as an adjunct to management of diabetes. Patients expected little co-operation from internists. Barriers to fitting passport into organization of diabetes care.	Feedback and monitoring Antecedents (Adding objects to the environment)
49	UK	PFCC: Care planning	Care planning meetings including older adults	Focus groups of 20 care providers	Benefits of collaborative decision-making confirmed, although concerns about the quality of participatory practices, limited attention to group process and exclusion of those with cognitive impairment were identified	Goals and Planning
50	US	PFCC: Communication	Families invited to be present during attempted resuscitation	Survey of 70 family members	94% would participate again; 76% said grieving was facilitated by witnessing the resuscitation; 64% felt	Antecedents (Restructuring the social environment)

					their presence was beneficial to the patient	
51	US	Patient Safety	Personalized bedside screensaver of a patient safety plan that captured data from the electronic health record, including icons common to geriatric syndromes.	Phase 1: 21 end users including 6 patients participated in interviews. Phase 2: 22 end users including 6 patients participated in interviews	The Meaningful Use Program in the US requires providers to engage their patients in their health care through technology. Patients and families did not question the data on the screen saver, although some providers questioned its accuracy. Generally viewed positively, although additional work remains to be done on functionality.	Antecedents (adding objects to the environment)
52	UK	Patient Safety	“Clean Your Hands” Campaign. Study measured the effect of MRSA awareness or knowledge on patients’ willingness and comfort level in asking staff about hand-washing.	Survey of 185 patients with a response rate of 58.9% (n=109)	Access and availability of patient information about the campaign was absent. Patients were knowledgeable and aware of risks of infect while hospitalized.	Shaping knowledge Antecedents (adding objects to the environment)
53	US	PFCC: Care Environment Programs	Structured patient-centred care and engagement training program and web-based technology including ICU safety checklist, tools to develop a shared care plan and messaging platform	Prospective pre-post study of 1,030 pre and 1,075 post patient admissions	Aggregate rate of adverse events dropped by 29% during the intervention period. Patient/family satisfaction improved markedly from 71.78 to	Antecedents (Restructuring the social environment; Adding objects to the environment)

			were used by patients and care partners to view health information, participate in their care plan and communicate with care providers.		93.3 for patients. No changes were found in care plan concordance or resource utilization.	
54	US	PFCC: Communication	Electronic Bedside Communication Centre (eBCC) prototype to activate patients and bridge communication gap with professionals	Individual interviews and focus groups	The eBCC was useful and easy to use, but there were issues trying to message the team and the ability to participate in developing the plan of care. Toolkit may be confusing for older patients or those uncomfortable with technology.	Antecedents (adding objects to the environment)
55	Norway	Care Coordination	Meeting Point program consists of three seminars and four follow-up meetings with health professionals from diverse settings focused on enhancing patient participation in transitional care.	Written feedback from 85 health professionals, minutes from the plenary sessions, log reports of group facilitators and participants' written notes. Follow-up meetings were recorded and transcribed.	Program was useful in increasing providers' awareness of and competencies related to the patient's perspective in transitional care.	Shaping knowledge Identity (Framing/re-framing)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15	56	Denmark	PFCC: Care Environment Programs	Psychiatric patients with a contract can initiate a brief admission without a health professional gatekeeper	190 patients evaluated 492 admissions. The majority sought early help for mental health conditions, but also for social and everyday problems.	Primary reason was to be at peace and prevent symptom increase. Two-thirds of the patients were satisfied, although those who hoped to improved medication or wished to obtain more care were less satisfied.	Feedback and monitoring (Self-monitoring of behavior) Antecedents (Restructure the social environment)
16 17 18 19 20 21 22 23 24 25 26 27 28	57	UK	PFCC: Care Environment Programs	Developed charters, information packages, health professional visibility strategies for cardiac patients. Flexible family visiting, facilitated and supported carer involvement in care provision and improved partnership between carers and team	Pre-post intervention surveys of 43 patient and 63 carers pre- and 56 patients and 68 families post	Improved carer recognition and increase in degree they felt listened to, included, involved and supported. Noted reduction of complaints to 0 over intervention period, supporting the finding of better communication.	Antecedents (Restructure the social environment; adding objects to the environment) Social support (Practical and emotional)
29 30 31 32 33 34 35	58	US	Patient safety	Patient-held, patient-friendly medication schedule with printed reported reviewed with patients	Surveys of 100 patients	Providing patients with schedule made them partners in health care decision and provided them with knowledge about medications.	Antecedents (adding objects to the environment)
36 37 38 39 40 41 42 43 44 45 46 47	59	UK	PFCC: Communication	Trauma patients view radiographs on tablets	Pre- and post-intervention study of 2 cohorts of 50	Post-intervention patients reported significant increase in scores for perceived involvement in	Antecedent (Adding objects to the environment; restructuring

				consecutive patients	decisions made about their care and being given the right information	the social environment)
60	AU	PFCC: Communication	Care bundle for medical and surgical patients: Checklist/brochure, video and posters developed by health professionals, researchers and patients	Interviews of 11 patients who had used the care bundle	Care bundle generally well-received by patients, although they did not make use of the checklist	Shaping knowledge Antecedents (adding objects to the environment)
61	AU	PFCC: Communication	Point of service feedback using paper-based or electronic questionnaires	Cross-sectional survey of 247 patients and 221 staff	Patients preferred to give feedback during stay rather than after discharge, give feedback verbally rather than by questionnaire. Some patients feared reprisal if they gave negative feedback. Staff agreed patients should be invited to give feedback during stay. Primary reason to provide feedback was to improve services. Feedback varies with data collector.	Antecedents (adding objects to the physical environment)
62	Canada	PFCC: Care Environment Programs	Enhanced Recovery after Surgery (ERAS) is a 22 element program designed to reduce morbidity and length of hospital stay.	20 patients who had undergone colorectal surgery in past 12 months	Overarching concept was that patients wanted to take responsibility for own health from diagnosis	Shaping knowledge Natural consequences

			Many of the elements are dependent upon patient adherence. Patient engagement framework developed. Goal was to build patient capacity within the ERAS program.	participated in patient-led focus groups and interviews. Seven patients participated in a co-design focus group to set and prioritize the research.	to recovery. Concluded no single model for patient engagement can be developed due to different cultures and contexts.	
63	US	PFCC: Communication	“Condition H” allows patients and families to initiate call to Rapid Response Team themselves.	Interviews with 21 patients and families involved with 21 Condition H events	Patients and families unanimously favorable. Most calls were related to communication issues or disagreement with treatment.	Feedback and monitoring Antecedents (Restructuring social environment; adding objects to the environment)
64	US	PFCC: Communication	Tablets used to provide health education modules (safety and discharge) and provide access to personal health records	Survey of 30 patients	Majority reported high overall satisfaction with the device, required <30 minutes of orientation. 83% completed safety module and 70% accessed their hospital record.	Antecedents (Adding objects to the environment) Shaping knowledge Feedback and monitoring
65	US	PFCC: Care Environment Programs	Wellness approach and focus on empowering medical patients/families during their stay. Live-in	Costs and health care utilizations data over 10 years	Reduced lengths of stay. 38.4% savings per hospitalization. Requires strict criteria and appropriate space.	Social support Antecedents (Restructuring the social environment)

			family or friend care partner actively involved in care.			
66	Germany	PFCC: Communication	Five one hour training sessions, including practice and feedback, for psychiatric patients on shared decision-making, including motivational and behavioral aspects	Randomized controlled trial of 61 inpatients (32 in intervention group). Control group received cognitive training.	Shared decision making training resulted in high participation preferences and increased desire to have more responsibility in treatment. Patients receiving intervention became more skeptical and were perceived as more "difficult" by psychiatrists.	Shaping knowledge Repetition and Substitution Feedback and monitoring
67	AU	Patient Safety	Patients and staff falls prevention education program ("Safe Recovery Program") comprised of DVD, workbook and 1-3 individualized sessions with physiotherapists that had been delivered to 750 patients	Qualitative exploratory study (N=10) with 9 participating in focus groups and 1 in telephone interviews, field notes	Individualized falls prevention education provides patients with capability and motivation to develop and undertake behavioral strategies to reduce falls. Educators could participate in engagement and reconciliation with staff to improve communication and outcomes.	
68	Japan	Effective Treatment	Daily voluntary training in addition to standard rehabilitation.	Clinical trial with 29 participants (21 intervention)	Voluntary training with family participation reduced length of stay and improved the rate of home discharge	Shaping knowledge Feedback and monitoring

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						Repetition and Substitution
69	US	PFCC: Communication	Evidence-based communication intervention bundles at 24, 72, 96 hours after admission to ICU. Included introduction to staff, resource folder, video, pain education, care model, resources.	Pre- and post-test design using process improvement methods. 41 pre-intervention surveys and 48 post-intervention surveys.	Family satisfaction scores for participation in decision-making and ratings of how well the team worked together showed statistically significant improvement following the intervention.	Shaping knowledge Antecedent (Restructuring social environment) Antecedents (adding objects to the environment)
70	Sweden	PFCC: Communication	Detailed written information regarding possible complications of surgery	Surveys of 182 (intervention) and 156 (control) patients undergoing surgery.	Majority of both intervention and control groups wanted more information about both common and rare complications. Intervention group significantly more satisfied with all aspects of information compared to control group both pre- and post-op.	Shaping knowledge Antecedents (adding objects to the environment)
71	US	PFCC: Care Planning	Families of ICU patients invited to participate in daily interdisciplinary rounds where team discussed plan of care.	Survey of 227 family members before and after implementation of family rounds.	Overall satisfaction scores did not differ between families who attended rounds and those who did not. Certain elements of	Antecedents (Restructuring the social environment)

					satisfaction improved, but overall satisfaction. Some families can benefit, but some feel rushed to make decisions.	
72	Sweden	PFCC: Communication	Patient-written "Tell-us" card (indicate what was most important for the patient that day) on patient perceptions of quality of care.	Quasi-experimental design using consecutive sample of 310 patients	Use of the Tell-us card resulted in significant improvements in 5 out of 17 items related to participation in decisions about medical and nursing care.	Feedback and monitoring Antecedents (Restructuring the social environment) Antecedents (adding objects to the environment)
73	Sweden	PFCC: Communication	"Tell-us" cards were used by patients to write goals for the day and indicated what mattered to them.	Interviews with 198 patients and 5 nurse managers	No improvements noted in patient participation, although culture shift noted in which staff grew to accept patients' involvement in their own care.	Feedback and monitoring Antecedents (Restructuring the social environment) Antecedents (adding objects to the environment)
74	Canada	PFCC: Bedside nursing handover	Shift hand-over conducted at medical-surgical and Ob/Gyn patients' bedsides.	Interviews with 45 patients.	Themes: creating a space for personal connection; enabled	Antecedents (Restructuring

					patients to be kept up to date; varying preferences (some patients did not see the need for bedside hand-over).	the social environment)
75	Canada	Patient Safety	Awareness campaign with 5 key safety tips for patients.	Survey of 108 hospital stakeholders (e.g. directors) and focus groups with the public.	Stakeholders were enthusiastic, although patient awareness of the campaign was low.	Shaping knowledge Antecedents (adding objects to the environment)
76	Finland	PFCC: Care Environment Programs	Activation programs for informal caregivers (booklets, invitation to participate in care); policy change (participate in an annual conference with other relatives and visitors, staff, researchers)	Interrupted time-series design with control groups of 369 caregivers conducted in 3 settings (university hospital; geriatric unit of a health centre and a nursing home)	Total participation of caregivers increased in long-term care, but not in the hospital.	Shaping knowledge Social support Antecedents (adding objects to the environment)
77	AU	PFCC: Care Environment Programs	New practice standards designed to encourage participation.	Survey of 86 community patients. Pre-post chart audits of 30 inpatient and 25 community	Modest and consistent improvements in documented carer participation were found.	Antecedents (Restructure the social environment; adding objects to the environment)

				patients (pre-), and 30 inpatients and 29 community patients (post-).		Goals and Planning
78	Germany	Patient Safety	“Patients and Families as Teachers in Patient Safety” brought interprofessional clinicians together with patients and families in 4 hour collaborative learning experience, including simulation, focused on developed patient-centred medical error disclosure communication skills.	Mixed methods with pre-post survey with qualitative and quantitative items. 55 clinicians and 18 patients and family members completed the program.	Bringing clinicians, patients and families together to discuss medical error was acceptable and feasible. Patients and families wanted to know “how the provider thinks” and more about medical error. They were interested in strategies for partnering with clinicians for safety. Patients valued experiencing clinicians’ send of accountability following medical mistakes; gained insight into the emotional impact of making an error for clinicians;	Antecedents (restructure social environment) Shaping knowledge Repetition and substitution Comparison of behavior (demonstration)
79	US	PFCC: Communication	“Go Wish” card game designed to allow seriously ill patients to consider the importance of common issues at the end of life so	Observational study of 67 patients using survey and patient rankings of goals and	25% of patients were able to complete the game. Highest value was “to be free of pain”. The card game is	Goals and Planning Antecedents (Adding objects to the environment)

			patients are prepared for discussions.	values after the game	feasible for use in inpatient settings.	
80	UK	Patient Safety	Patient Reporting and Action for a Safe Environment (PRASE) intervention consisted of: a) Patient Measure of Safety (PMOS) Questionnaire and b) a form for patients to report both safety concerns and positive experiences (patient incident reporting tool). Feedback considered in team meetings.	Clusters included 33 hospital wards within 5 hospital.	No significant effects on ward-level harm-free care and patient-level feedback on safety. Intervention uptake and retention was 100%.	Antecedents (Adding objects to the environment) Feedback and monitoring
81	UK	Effective treatment	“GetREAL” program for psychiatric patients in rehabilitation programs with predisposing, enabling and reinforcing stages	Qualitative study of 59 patients using focus groups of staff within a clustered RCT.	Intervention accepted by staff, but skills and changes to processes and structures were not sustained at the conclusion of the program. External factors such as resources limitation, lack of senior staff support, competing priorities and intensive training contributed to findings.	Antecedents (Restructuring the social environment; adding objects to the environment) Goals and planning (Commitment) Repetition and substitution
82	US	Patient Safety	Patients presented with a “Partners in Your Care” script asking them to remind health care workers to wash their hands; compliance reassessed using a modified	Interviews and direct observations of 193 patients.	Only 3% reminded at least one worker to wash their hands and 8% did not comment on hand hygiene after observing workers fail	Antecedents (adding objects to the environment) Feedback and monitoring

			script where patients were asked to thank workers for washing and/or display a sign saying "Thanks for Washing"		to wash hands. Patients are unlikely to remind workers to wash their hands.	Association (prompts and cues)
83	US	PFCC: Communication	Alert ICU patients or family members of patients who met criteria for physiological or anatomic activation of the trauma team with subsequent resuscitation were offered the option of families being present during resuscitation.	Analysis of self-administered survey of a convenience sample of family members of 140 trauma patients (70 not present during resuscitation).	Being present during resuscitation associated with reduced anxiety, reduced stress and fostered well-being,	Shaping knowledge Antecedents (restructuring the social environment)
84	Sweden	PFCC: Communication	Geriatric patients invited to team meeting which replaced rounds.	Phenomenological study with 9 nurses	Patient participation can be supported by a safe relationship in which the patient can make his or her voice heard. Participated is challenged by patients' vulnerability and by the subordinated role assigned to the patient.	Antecedents (Restructuring the social environment)
85	Canada	PFCC: Care Environment Programs	Established peer support program for psychiatric patients, strengthened patient advisory committee and creating a patient-led research team	Prospective, longitudinal approach (T1 and T2) with 25 patients. 28 providers were surveyed at T1 and T2.	Intervention had minimal impacts on internalized stigma, personal recovery, personal empowerment, service engagement, therapeutic milieu and	Social Support Antecedents (Restructuring the social environment)

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					recovery orientation of services.	
86	UK	Patient Safety	Patient Reporting and Action for a Safe Environment (PRASE) consisting of Patients Measure of Safety (PMOS) and Patient Incident Reporting Tool (PIRT) enables patients to reported detailed safety concerns and/or positive experiences. Anonymous feedback collecting using these tool present to ward staff in the form of a feedback report, followed by iterative planning cycle.	Focus groups with hospital volunteers (n=15), voluntary and patient experience staff (n=3). Semi-structured interviews with ward staff (n=5).	All stakeholders were positive about the PRASE intervention as a way to support service improvement and the benefits of including volunteers. Volunteers felt adequate training and support would be essential for retention. Staff raised concerns about infrastructure and sustainability.	Antecedents (adding objects to the environment) Feedback and monitoring
87	Spain	Effective Treatment	Individualized graduated exercise program with monitoring. Education of patients, caregivers and staff to promote mobility and functional independence	Prospective clinical trial of 17 intervention and 12 control participants.	An early supervised exercise program can reduce decline and can be maintained or improved when families are involved.	Feedback and monitoring Shaping knowledge Antecedents (adding objects to the environment)
88	UK	Patient Safety	“Partner in Your Care” program where medical-	Controlled prospective	62% of patients felt comfortable asking	Feedback and monitoring

			surgical patients asked all healthcare workers who were going to have contact with them "Did you wash your hands?"	intervention study of 39 patients. Compliance measured through soap/alcohol usage and handwashings per bed.	about handwashing. All patients asked nurses, but only 35% asked physicians.	Shaping knowledge
89	AU	PFCC: Bedside nursing handover	Nursing bedside handover	Descriptive case study of 10 patients	Patients appreciated being acknowledge as partners in care. Bedside handover was the opportunity to correct inaccuracies in information being communicated. Some patients preferred passive engagement.	Antecedents (Restructuring the social environment)
90	Norway	PFCC: Care Environment Programs	Government-legislated patient participation in care	Interviews with 15 older adults admitted to geriatric wards.	The values of older adults of community and solidarity may differ from the focus on individualism that underpins legislation. Patients often authorized family members to act and participate on their behalf due to their own declining capabilities and the hospitals' busy schedules.	Goals and Planning Antecedents (Restructuring the social environment)

91	UK	Patient Safety	Call 4 Concern is a scheme where patients and relatives can call critical care teams if they are concerned about a patient's condition.	Surveys completed by 11 patients transferring out of ICU to general wards over a six month period, 11 relatives and 4 others and 57 ICU staff members.	Patients and families felt reassured. Staff felt the system could prevent deterioration, but were concerned about inappropriate calls, increased workload and de-skilling of ward staff.	Antecedent (restructure social environment) Shaping knowledge
92	US	PFCC: Communication	Given tablets with a mobile patient portal application including pictures, names and role descriptions of team members, scheduled tests, procedures and a list of active medications.	100 intervention and 102 control-unit participants.	Significantly higher proportions of intervention named more than one physician and physician role. No difference in knowledge of nurses' names, planned tests, procedures or medications were noted between the units. No change in activation score.	Shaping knowledge Antecedents (Adding objects to the environment)
93	Finland	PFCC: Care Environment Programs	Mental health patients who are well-known to providers can refer themselves to short inpatient stays.	42 qualitative, semi-structured interviews with 28 patients with serious mental illness	Having the option to self-refer enhanced patients confidence in the services they use and in their own ability to cope with everyday life.	Antecedent (restructure the social environment) Feedback and monitoring (self-monitoring)

94	US Canada	PFCC: Care Planning	Morning interprofessional rounds used in critical care to improve team-based care, patient outcomes and involve patients and families.	Ethnographic study with 576 hours of observation, 47 shadowing experiences and 40 clinician interviews.	Rounds conducted at threshold of patient room, rather than inside of them. Involving patients was seen to “inevitably and uselessly prolong rounds”. Patient interactions were rare. Physicians felt time constraints necessitated more time spent teaching interns and less on interacting with or including patients in their own care.	Antecedents (Restructure the social environment)
95	US	PFCC: Communication	Detailed, personalized information about injuries, acute care treatment and rehabilitation progress was provided.	2x2 factorial design with 28 patients.	Intervention patients exerted greater effort in physical therapy, made greater improvement in functional independence and were more satisfied with rehab treatment.	Shaping knowledge Antecedents (Restructure the social environment; adding objects to the environment)
96	UK	Patient Safety	A 4 minute animated video entitled “PINK” aimed at helping patients prevent errors by encouraging them to : Participate; Be informed; Notice and Be alert; and Know what they	Qualitative semi-structured interviews with 36 patients	Overall favorably received. Benefits included raising awareness and facilitating patients to be involved in care. Less certainty about its	Antecedents (adding objects to the environment) Shaping Knowledge

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			can do to facilitate their recovery		ability to enhance safety. Different groups may require more tailored content in videos.	Comparison of behavior (demonstration)
97	Canada	PFCC: Care Environment Programs	“Patients as Partners” concept in programming considers medical patient full-fledged members of health care team. Uses competencies and practices for both patient and providers.	Grounded theory study with 16 semi-structured patient interviews of those who participated as “patient trainers’ co-leading inter-professional collaboration courses.	Patients described themselves as: a) continuously learning about their health; b) assessing the quality of health care received and c) adapting and compensating for optimal or non-optimal care, taking more control over decisions with their own care.	Antecedents (Restructure the social environment)
98	Norway	PFCC: Care Environment Programs	Development plan in one mental health hospital (intervention) included: establishing a patient education center, a user office, purchasing user expertise, appointing contact professionals for next of kin, improve center’s information and culture	Non-randomized controlled study using a survey of 438 professionals to compare outcomes between intervention and 2 control groups in different hospitals.	No statistically significant differences in professionals’ knowledge, practice or attitudes.	Antecedents (restructure the social and physical environments; adding objects to the environment)

1 2 3 4 5 6 7 8 9 10 11 12 13	99	Norway	PFCC: Care Environment Programs	Development plan in one mental hospital (intervention) included: establishing a patient education center, a user office, purchasing user expertise, appointing contact professionals for next of kin, improve center's information and culture	Survey of 1651 patients	No statistically significant effect on the patients' experience of user participation	Antecedents (Restructure the social and physical environments; adding objects to the environment)
14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	100	Israel	PFCC: Care Planning	Ward (medical) rounds were conducted with and then without the presence of family members.	Prospective 2-phase survey study of 26 (phase 1) and 23 (phase 2) nurses and physicians, 26 and 35 patients and 32 and 40 family members	Hospitalized patients wanted family members to participate in rounds. Staff were initially reluctant, but gradually more accepting. Patients felt they had a better understanding of their medical conditions. Families felt they had more opportunity to participate in decision-making. Adjustment to the structure of rounds is necessary.	Antecedents (Restructure the social environment)
32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47	101	US	PFCC: Communication	Computer-processed information about geriatric patient preferences for self-care capability were placed in the patients' charts for staff to use in care planning.	Three group quasi-experimental design with one experimental and 2 control groups (n=151)	Information about patient preferences changes nurses' care priorities to be more consistent with patient preferences and improved patients' preference	Shaping Knowledge Goals and Planning Antecedents (adding objects to the environment)

					achievement and physical functioning	Feedback and monitoring
102	Norway	PFCC: Care Environment Programs	CHOICE is a palm-based decision support system for preference-based acute care planning that elicits patient preferences for functional performance at the bedside and to select care priorities consistent with patient preferences	Three group quasi-experimental design with one experimental and 2 control groups	Nurses' use of CHOICE changed nursing care to be more consistent with patients preferences and improved patients' preference achievement	Goals and Planning Antecedents (Restructuring the social environment; adding objects to the environment)
103	US	PFCC: Bedside nursing handover	End-of-shift report at patient bedside. Training video, hand-outs, scripts for handovers provided to nurses.	Pre- and post-survey of 232 (pre) and 178 (post) patients, 70 (pre) and 72 (post) family members and nurses. Data on Patients falls during shift change, medication errors and nurse overtime was also collected.	Statistically significant difference in patients feeling included in shift report and believing that important information was communicated between shifts. Both falls and medication errors during shift change decreased. Improved nurse perceptions of nursing accountability and patient involvement in care.	Shaping knowledge Antecedents (Restructure social environment; adding objects to the environment)
104	Singapore	Effective treatment	Patient education intervention to enhance self-efficacy of hospitalized medical patients to recognize and report symptoms of acute deteriorating conditions	Cluster RCT of 34 (intervention) and 33 (control) patients.	Level of self-efficacy in experimental group was significantly higher than control group.	Shaping knowledge Antecedents (Restructure the social environment; adding objects

						to the environment)
105	US	PFCC: Communication	Whiteboards at medical patients' bedside can be a communication tool between hospital providers and a mechanism to engage patients in care	Survey of 104 nurses, 118 house staff and 31 hospitalists	While providers valued family contact information on the whiteboard, nurses valued the importance of goals and discharge dates more than physicians. Few providers felt patients or families should be responsible for the information on the board or be involved in creating goals.	Antecedents (adding objects to the environment) Goals and Planning
106	US	PFCC: Care Environment Programs	Engagement of nurses, physicians, administrators and security in creating open visitation policy in acute care and rehabilitation hospital.	14,444 after-hours visit recorded	No increase in number of complaints from patients or visitors. Security event numbers remained the same. Unit staff received few phone calls for patient updates. Patient satisfaction scores showed positive trends but no significant change.	Antecedents (Restructure the social environment)
107	US	Effective treatment	Telephone-administered health behavior change counseling (brief motivational interviewing) of surgical patients.	Prospective clinical trial of 59 (control) and 63	Patient activation predicted engagement. The influence of counseling on rehab engagement was	Social support Regulation Antecedents: Restructuring

				(intervention) patients	mediated by patient activation.	the social environment
108	US	PFCC: Communication	Psychiatric patients given daily access to medical records with a nurse available to assist.	Survey of 88 patients and 20 staff	Patients reported feeling better informed and more involved in their treatment. Staff said they became more thoughtful about their notes.	Antecedents (Restructure the social environment)
109	Sweden	PFCC: Care Planning	Medical patient participation in ward rounds	Descriptive study of 14 inpatients who participated in interviews.	Aspects of ward rounds could be improved to promote information exchange. Information from nurses was easier to understand than information from physicians. Rounds must have an open atmosphere. Patients must be treated with empathy by staff and their right to participate acknowledged.	Antecedents (Restructure the social environment) Goals and Planning
110	Finland	PFCC: Care Planning	Afternoon reporting at surgical patients' bedsides	Survey of 118 nurses and 74 patients with observation of 76 bedside reporting sessions	Three minutes were used to give each patients' report. Patients felt this time was too short. One third of patients felt uncomfortable when other patients were present. Differences between nurse and	Antecedents (Restructure the social environment) Feedback and monitoring

					patient perceptions in terms of purpose of rounds and whether patients were to participate.	
111	Austria	PFCC: Care Environment Programs	Training program aimed at providers for empowering cardiac patients to be more effective co-producers of recuperation from surgery. 2 hour didactic session for all staff and additional 3 hour training for physicians which included role play, supervision of 3 ward rounds, admission and discharge communications.	Case study of 100 (control) and 99 (intervention)	Length of stay reduced by 1 day, incidence of post-surgical tachyarrhythmias reduced by 15%, transfer speed improved and patient rating of provider communication were improved.	Shaping knowledge Antecedents (Restructure the social environment)
112	UK	Patient Safety	"Medicines with Respect" program provided a foundation for the administration of medication and medication management strategies with client involvement. Skills training for nurses, assessment and set of clinical guidelines.	67 patient questionnaires and unspecified number of staff evaluations.	More patients were given written information; being given their medication individually instead of in a queue; improved patient compliance with medications; more carers were given sufficient information. No difference in explanations for rational for medication or patient understanding.	Antecedents (restructure social environment) Antecedents (adding objects to the environment)

113	The Netherlands	PFCC: Care Environment Programs	SAFE or SORRY program consisted of essential recommendations from guidelines on the prevention of three adverse events (pressure ulcer, falls and urinary tract infections) prevalent in older adults. Education, patient involvement and feedback occurred through a computerized registration system.	Cluster RCT of 10 wards from 4 hospital with 2201 patients and ten wards from six nursing homes with 392 patients.	Hospitalized patients receiving the intervention suffered 43% fewer adverse events than control groups. Rate ratios for the development of an adverse events were statistically significant (OR=0.57, CI 0.34-0.95) for hospital patients receiving the intervention.	Shaping knowledge Antecedents (adding objects to the environment) Feedback and monitoring
114	Sweden	PFCC: Care Planning	The Canadian Occupational Measure (COPM) is a patient-centred instrument that provides a structure for formulating treatment goals identified by the client in cooperation with the occupational therapist through an interview.	Experimental design with 155 patients in the intervention group and 55 in the control group. Structured interview with 88 patients in the intervention and 30 in the control group.	Compared to the control group, more patients in the experimental group perceived that treatment goals were identified, felt they were active participants in the goal formulation process and perceived themselves better able to manage after completed rehabilitation.	Goals and Planning Antecedents (Restructure the social environment) Antecedents (adding objects to the environment)
115	UK	PFCC: Care Planning	Goal-setting meetings for rehabilitation patients.	Qualitative study of 4 cohorts of 10 patients, carers or staff with different	All groups found goal setting beneficial, increasing motivation and providing reassurance for patients and carer.	Goals and Planning Antecedents (Restructure the social environment)

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				experiences in goal-setting	Carers found goal setting alleviated anxieties and assisted active problem-solving coping strategies. Staff believed goal setting made their practice more focused and collaborative,	Social support
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For peer review only

BMJ Open

Building patient capacity to participate in care during hospitalization: A scoping review

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3 **Building Patient Capacity to Participate in Care during Hospitalization:**
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Abstract

Objectives: To map the existing literature and describe interventions aimed at building the capacity of patients to participate in care during hospitalization by: a) describing and categorizing the aspects of care targeted by these interventions; and, b) identifying the Behavior Change Techniques used in these interventions. A patient representative participated in all aspects of this project.

Design: Scoping review.

Data sources: MEDLINE, Embase and CINAHL (Inception -2017).

Study Selection: Studies reporting primary research studies on building the capacity of hospitalized adult patients to participate in care which described or included one or more structured or systematic interventions and described the outcomes for at least the key stakeholder group were included.

Data Extraction: Title and abstract screening and full text screening were conducted by pairs of trained reviewers. One reviewer extracted data, which was verified by a second reviewer. Interventions were classified according to seven aspects of care relevant to hospital settings. Behavior change techniques identified in the articles were assigned through consensus of three reviewers.

Results: Database searches yielded a total 9,899 articles, resulting in 87 articles that met the inclusion criteria. Interventions directed at building patient capacity to participate in care while hospitalized were categorized as those related to improving: patient safety (20.9%); care coordination (5.7%); effective treatment (5.7%); and/or patient-centred care using: bedside nursing hand-overs (5.7%); communication (29.1%); care planning (14%); or the care environment (19.8%). The majority of studies reported one or more positive outcomes from the defined intervention. Adding new elements (objects) to the environment and restructuring the social and/or physical environment were the most frequently identified Behavior Change Techniques.

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3 **Conclusions:** The majority of studies to build capacity for participation in care report one or more
4
5 positive outcomes, although a more comprehensive analysis is warranted.
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9 **Strengths and Limitations of the Study**
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- 13 • Identification of behavior change techniques used in included studies highlights the importance
14 of behavior change as foundational in interventions designed to build hospitalized patient
15 capacity to participate in care.
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 - 18 • Because building capacity of hospitalized patients to participate in care can take many forms,
19 the aims, interventions and study designs included in this review were heterogeneous and
20 largely descriptive.
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 - 23 • Exclusion of grey literature, articles published in languages other than English and articles
24 published after August, 2017 are limitations of the study.
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 - 27 • Formal measurement of agreement levels between coders was not performed during the coding
28 training sessions.
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 - 31 • Patient focus groups were not included in the scoping review process. Additional patient
32 representatives on this project may have contributed to broader patient perspective.
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44 **Keywords:** Patient participation; patient-centred care: behavior change techniques; hospitals; quality
45 improvement
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47 Word Count: 3886
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For peer review only

1. Introduction

Improving the safety, quality and patient-centredness of care delivered in hospitals is well-recognized as a global priority ^{1,2}, with increasing recognition of the potential of patient engagement to contribute to the improvement agenda. ^{3,4} Patient engagement is defined by the WHO as “the process of building the capacity of patients, families, carers and health care providers, in order to enhance safety, quality and patient-centredness of health care delivery”.⁵

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3 Effective engagement of patients in care provided during hospitalization has been associated
4 with better self-management,⁶⁻⁷ fewer adverse events,⁸ and diagnostic tests,⁹ decreased use of health
5 services,¹⁰ and shorter lengths of stay.¹¹ Patients and families who are engaged in care have
6 opportunities to provide information essential to appropriate care planning,¹² to recognize errors in
7 care delivery,¹³ and to adhere to treatment plans.¹⁴ Additional benefits of effective patient and family
8 engagement include: enhancing system responsiveness to evolving user needs¹⁵; promoting decision-
9 making transparency and improving quality^{16,17}; and reducing cost and waste.¹⁵

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19 The quality challenges common to health care systems include the need to improve patient
20 safety, patient-centred care, coordination of care, effective prevention and treatment, healthy living and
21 care affordability.¹⁸ Within hospital settings, high acuity and rapid patient turn-over represent barriers
22 to effective patient participation in care to an extent not found in other health care settings. Wide
23 variability in the implementation of practices designed to promote patient and family engagement was
24 identified in a survey of U.S. hospitals.¹⁷ These practices were classified into the following categories: a)
25 organizational (e.g., formal policy for disclosing medical error); b) bedside (e.g., participation in shift
26 change report); and, c) access to information and shared decision-making (e.g., online access to personal
27 health information).

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39 Better understanding of the characteristics of interventions aimed at building the capacity of
40 hospitalized patients to participate in care is important for building the evidence base in this area and
41 strengthening the theoretical underpinnings of future interventions at the design phase. Successful
42 implementation of these types of interventions may be facilitated by the incorporation of systematic
43 methods such as behavior change techniques (BCTs) for characterizing interventions and linking these to
44 an analysis of the targeted behavior.^{19,20} BCTs are defined as “observable, replicable and irreducible
45 component[s] of an intervention designed to alter or redirect causal processes that regulate behavior”.

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¹⁹ The BCT Taxonomy can offer a reliable and systematic framework for the identification of the “active,

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3 effective” components within specific interventions ¹⁹, provided sufficient detail is provided about the
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5 intervention. ²¹
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8 Given the dynamic state of evidence describing interventions to promote patient participation, a
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10 scoping review was the most appropriate method to produce a narrative integration of relevant
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12 evidence addressing our broadly defined question. ²¹ Although efforts to intentionally build capacity to
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14 participate in care have become a priority in many hospitals, much remains to be learned about how to
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16 best accomplish this goal. *In order to advance the evidence base in this area, this scoping review aimed*
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18 *to map the existing literature and describe interventions aimed at building the capacity of patients to*
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20 *participate in care during hospitalization.* Our specific research questions were to: a) describe and
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22 categorize the aspects of care targeted by these interventions; and b) identify the behavior change
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24 techniques used in the interventions to build patient participation in care.
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27 28 **2. Methods**

29 30 31 *2.1 Design*

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33 As one form of knowledge synthesis, scoping reviews provide narrative integration of relevant
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35 evidence by mapping key concepts, types of evidence and gaps in research to address a broad question
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37 investigating a particular field. ²² To date, there have been no syntheses of the interventions designed to
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39 build capacity of hospitalized patients to participate in care. The original protocol for this review was
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41 published in 2018.²³
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45 This systematic scoping review has allowed us to determine the extent, range and nature of
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47 research activity related to initiatives designed to build the capacity of hospitalized patients to
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49 participate in care. Guided by the methodology proposed by Arksey and O’Malley ²² and its subsequent
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51 revisions, ^{24,25} this review included the following steps: a) identifying the research question; b)
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53 identifying relevant studies; c) describing study selection criteria; d) charting the data; and e) collating,
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3 summarizing and reporting the results. In keeping with other scoping reviews in which the research
4 team is large and multi-disciplinary,²⁶ we did not undertake the optional step of consultation. To further
5 outline the methodology, a completed PRISMA-SCr Checklist²⁷ for scoping reviews has been attached.
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7 Because scoping reviews seek to understand topics of significant complexity in a broad area, rather than
8 synthesize only the best available evidence, a quality appraisal of included studies was not performed.²²
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14 **Patient and Public Involvement**

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17 A patient who was also a retired university professor (MS) with an education background was a
18 member of the research team. He was recruited to provide a patient's perspective.²⁸ The lack of patient
19 focus groups is recognized as a limitation of the study, however, the patient representative contributed
20 actively to all phases of the scoping review from inception. He shared his experiences within the system
21 and contributed to interpretation of the findings. We did not include patient focus groups in the
22 consultation process for this scoping review.
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31 *2.2 Identifying the Research Question*

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35 In collaboration with knowledge users from the provincial Health Quality Council and health
36 region in Saskatchewan, Canada, as well as decision makers from the Saskatchewan Ministry of Health,
37 the team identified the following question as the focus for this scoping review: **What are the**
38 **characteristics of interventions designed to build the capacity of hospitalized patients in addressing**
39 **key health care priorities reported in the literature?**
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46 *2.3 Identifying Relevant Studies*

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49 Following an initial scan of potentially relevant databases (including the Cochrane Database of
50 Systematic Reviews), MEDLINE, Embase and CINAHL were selected for use in this review as having the
51 best coverage of literature related to hospitals. A comprehensive electronic literature search was
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3 conducted by an experienced medical librarian (EW) in MEDLINE (through OVID), Embase (through
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5 OVID) and CINAHL Plus (through EBSCOhost) from inception to December 15, 2016 and updated August
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7 31, 2017. Our search strategy included the following key terms and synonyms: acute care; hospitals;
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9 caregivers; family; and patient participation, empowerment, engagement or involvement. Please see
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11 Supplementary File 1 for the comprehensive search strategy in MEDLINE. The reference lists of studies
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13 were examined to identify additional relevant articles.
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17 Literature search results were uploaded into Covidence™ Systematic Review Software ²⁹ after
18
19 removing duplicate references. This software provides a decision dashboard and annotation tool, as well
20
21 as the capacity to create forms for screening and extracting data. Additional duplicates missed by the
22
23 reference software were removed as identified. Studies were selected in two phases: a) title and
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25 abstract screening and b) full text screening/review.
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28 29 *2.4 Study Selection*

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32 Inclusion and exclusion criteria were developed based upon a preliminary literature review and
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34 the advice of knowledge users and decision-makers. In order to be included in this scoping review, the
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36 studies must have: a) taken place within a hospital setting (including inpatient rehabilitation); b)
37
38 described or included a structured or systematic approach to building capacity of patients to participate
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40 in care, including organizational practices, bedside practices or access to information practices; c)
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42 included adult patients only and d) described the outcomes of the interventions from any one of the
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44 following stakeholder perspectives: patients and families; health care providers; health systems; or
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46 administrators/funders. All study designs were included, provided that the studies adhered to the
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48 inclusion/exclusion criteria. We included only studies published in English for this scoping review, as this
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50 was the primary language spoken by team members.
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3 Papers addressing interventions to build capacity in the following populations were excluded:
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5 children and adolescents; community or home settings; oncology patients (because this group often
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7 experiences rapid transitions between community, outpatient and inpatient settings) and Emergency
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9 Department settings. We also excluded papers focused upon patient participation in research,
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11 databases, quality improvement (e.g. patient advisory councils) or health care service re-design; or
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13 patient needs, knowledge or activation assessments.
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17 Team training sessions for reviewers consisted of group screening of 20 titles. The inclusion and
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19 exclusion criteria were pilot-tested during the training session resulting in minor revisions to enhance
20
21 the clarity of descriptors and improve inter-rater reliability. Following this training, titles and abstracts
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23 were screened by two reviewers, one of whom was the PI (DG).²⁶ Discrepancies were resolved through
24
25 consensus between the reviewers.
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29 A second team training session for full text screening and review was held. Eight of the nine
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31 team members participated in full text screening and review, with EP serving as an arbitrator. Two
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33 researchers independently reviewed each of articles selected for full-text screening to ensure inclusion
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35 criteria had been met. Discrepancies were discussed between the researchers to achieve consensus and
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37 in one case, the dispute was resolved by the arbitrator.
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40 41 *2.5 Charting the Data* 42 43

44 A standard data extraction form created using Microsoft Word (Supplementary File 2) was pilot-
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46 tested in the team training session prior to data extraction. Use of this software, rather than the pre-set
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48 categories in Covidence, allowed us flexibility in data extraction categories and entries. Pairs of team
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50 members were randomly assigned to extract data from 20 articles. Key characteristics extracted by the
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52 two reviewers for each article included: a) study identification (author, year of publication, setting,
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54 country); b) focus of the intervention; c) description of the intervention; d) study design and
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3 participants; and e) study findings. All extracted data from each pair of team members were reviewed
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5 and confirmed by DG.
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8 In order to categorize the focus of each article, reviewers initially coded each article according to
9
10 the terms used by the authors (e.g. multidisciplinary goal setting). Two team members (DG and CH)
11
12 then assigned each article to one of seven categories adapted from the AHRQ National Quality Strategy
13
14 Priorities¹⁸ that reflected dominant themes of this corpus of literature: patient safety; care
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16 coordination; effective treatment; bedside nursing hand-overs; communication; care planning; and the
17
18 care environment.
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22 Coding of BCT categories and techniques occurred following the data extraction. Each article
23
24 was re-read by DG, MM and LN. BCT codes were assigned independently using the operational
25
26 definitions provided by the BCT taxonomy v1¹⁹ and the supplementary BCT coding framework reported
27
28 by Presseau et al.²⁰ There was no limit on the number of BCTs that could be identified. Discrepancies in
29
30 BCT assignment were discussed and consensus achieved.
31
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33 34 *2.6 Collating, summarizing and reporting the results*

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36 A narrative approach was used to collate, summarize and report the data. Summary statistics
37
38 were used to describe the number of studies by setting, country, year of publication, methods, focus
39
40 and BCTs identified.
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43 44 **3. Results**

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46 A total of 9,899 articles (9,239 on December 15, 2016 and 660 in the search update on August
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48 31, 2017) were identified after duplicates were removed through the search process (Figure 1).
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50 Following title and abstract screening, 503 remaining articles met our inclusion criteria and underwent
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52 full-text screening. During the full-text assessment, 416 were excluded because they did not meet one
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3 or more of the eligibility criteria (n= 319), did not report on a specific intervention (n= 36), or were
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5 conference abstracts (n=61).
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8 **3.1 Characteristics of included studies**

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11 Supplementary File 3 presents the summary of included studies (n=87).³⁰⁻¹¹⁷ Over half of these
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13 studies originated in either the U.S. (n=32, 36.8%) or the U.K. (n=17, 19.5%). Fifteen (17.2%) came from
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15 Scandinavian countries and eight from Australia (9.2%). Only five (5.7%) articles were published prior to
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17 2000.
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20 21 3.1.1 Study designs

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24 The studies included were methodologically diverse. Of the 87 included articles, three (3.4%)
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26 were randomized controlled trials examining outcomes of interventions designed to build patient
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28 capacity to participate in care coordination⁴⁰, communication⁶⁶ and effective treatment.¹⁰⁹ Three
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30 (3.4%) cluster randomized controlled trials were aimed at improving patient capacity to participate in
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32 safety initiatives⁸², recognize deteriorating condition¹⁰⁶, and the care environment.¹¹⁵
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36 The remaining studies included quasi-experimental designs, case-controlled studies (including
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38 the use of administrative data), interrupted time series, ethnographies, case studies, chart reviews and
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40 pre- and post-test designs. Qualitative and mixed methods approaches (n=29, 33.3%) and cross-
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42 sectional or pre- and post- interventions surveys (n=21, 24.1%) were used in over half of the included
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44 studies.
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47 3.1.2 Patient populations

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50 While a significant proportion of capacity-building interventions (e.g. safety, rapid response
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52 teams) were implemented across entire acute care hospitals, other studies were directed towards
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54 specific patient populations, such as critically ill (n=7, 8.0%)^{35, 52, 56, 71, 73, 85, 97}, geriatric (n=6, 6.9%)^{53, 78, 86},
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3 92, 103, 153, rehabilitation (n=9, 10.3%)^{48, 69, 70, 89, 97, 104, 108, 116, 117}, surgical (n=6, 6.9%)^{64, 72, 109, 112, 113} or
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5 psychiatric (n=8, 9.2%)^{34, 58, 68, 87, 95, 100, 101, 110} patients.
6
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8 3.1.3 Outcomes 9

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11 Positive outcomes were reported in two of the three randomized controlled trials^{40, 68} and two
12 of the three cluster randomized controlled trials^{106, 115}. Failure to achieve key study objectives were
13 reported in a number of the remaining studies.^{33, 50, 77, 82, 85, 87, 96, 100, 112} The remaining studies reported
14 one or more positive outcomes associated with the intervention to build hospitalized patient capacity to
15 engage in care.
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23 3.2 Aspects of care addressed by capacity-building interventions 24

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26 Interventions designed to build patients' capacity to participate were found to address seven
27 key aspects of care in hospitals. These aspects of care included: patient safety (n=18; 20.7%); bedside
28 nursing handovers (n=5; 5.7%); communication (n=25; 28.7%); care planning (n=12; 13.8%);
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30 modifications to the care environment to promote engagement (n=17; 19.5%); care coordination (n=5;
31 5.7%) and effective treatment (5; 5.7%).
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38 The interventions focused on patient safety addressed a range of safety issues including:
39 medications^{30, 39, 60, 77, 114}; falls^{30, 53, 69}; hand-washing^{30, 46, 47, 54, 84, 90}; surgical site identification³⁰; medical
40 error⁸⁰; or patient reporting and action^{32, 77, 82, 88, 93, 98}. Eleven (12.6%) studies incorporated a form of
41 information technology to build the capacity of patients to participate in care.
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47 One-third of the included studies (n=25; 28.7%) reported interventions designed to enhance
48 communication between patients and providers to promote participation in care. Examples included
49 interventions designed to encourage interactions between patients, families and providers^{35, 44, 52, 71}, to
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provide a means by which patients or families could communicate their wishes or concerns ^{74, 75, 81, 85} or to share clinical information with patients. ^{33, 61, 66, 72, 97}

Multi-component programs aimed at enhancing the environment in which patient-and family-care was delivered accounted for 17 (19.5%) studies. These interventions often involved new models of care specifically aimed at promoting patient-centredness using multiple interventions, such as the adoption of new standards of care. ⁷⁹

3.3 Behavior Change Techniques Identified to Build Patient Capacity to Participate in Care

Table 1 describes the types of behavior change techniques used to build capacity for each of the seven key aspects of care.

Table 1. Behavior Change Techniques Identified to Build Patient Capacity to Participate in Care (n=87)

Aspect of Care	References	BCT
Patient Safety (n=18)	30	Shaping knowledge Antecedents (adding objects to the environment)
	32	Antecedents (restructuring the physical and social environment; adding objects to the environment)
	39*	Antecedents (adding objects to the environment)
	46	Shaping knowledge Antecedents (adding objects to the environment)
	47	Shaping knowledge Antecedents (adding objects to the environment)
	53*	Antecedents (adding objects to the environment)
	54	Shaping knowledge Antecedents (adding objects to the environment)
	60	Antecedents (adding objects to the environment)
	67	Shaping knowledge Feedback and monitoring Repetition and Substitution (behavioral practice/ rehearsal)
	77	Shaping knowledge Antecedents (adding objects to the environment)
	80	Antecedents (restructuring social environment)

Aspect of Care	References	BCT
		Shaping knowledge Repetition and substitution Comparison of behavior (demonstration)
	82	Antecedents (adding objects to the environment) Feedback and monitoring
	84	Antecedents (adding objects to the environment) Feedback and monitoring Association (prompts and cues)
	88	Antecedents (adding objects) Feedback and monitoring
	90	Feedback and monitoring Shaping knowledge
	93	Antecedents (restructuring the social environment) Shaping knowledge
	98	Antecedents (adding objects to the environment) Shaping Knowledge Comparison of behavior (demonstration)
	114	Antecedents (restructuring the social environment)
Person- and Family-Centred Care: Bedside Nursing Handovers (n=5)	31	Shaping knowledge Antecedents (adding objects to the environment)
	37	Antecedents (restructuring the physical and social environments) Scheduled consequences
	76	Antecedents (restructuring the social environment)
	91	Antecedents (restructuring social environment)
	105	Shaping knowledge Antecedents (restructuring social environment; adding objects to the environment)
Person- and Family-Centred Care: Communication (n=25)	33*	Antecedents (adding objects to the environment)
	35	Shaping knowledge Social Support
	44*	Goals and planning Antecedents (restructuring the social environment; adding objects to the environment)
	48	Goals and planning
	50	Feedback and monitoring Antecedents (Adding objects to the environment)
	52	Antecedents (restructuring social environment)

Aspect of Care	References	BCT
	55*	Antecedents (restructuring the social environment; adding objects to the environment)
	61*	Antecedents (restructuring the social environment; adding objects to the environment)
	62	Shaping knowledge Antecedents (adding objects to the environment)
	63*	Antecedents (adding objects to the environment)
	65	Feedback and monitoring Antecedents (restructuring social environment; adding objects to the environment)
	66*	Antecedents (adding objects to the environment) Shaping knowledge Feedback and monitoring
	68	Shaping knowledge Repetition and Substitution (behavioral practice) Feedback and monitoring
	71	Shaping knowledge Antecedents (restructuring the social environment; adding objects to the environment)
	72	Shaping knowledge Antecedents (adding objects to the environment)
	74	Feedback and monitoring Antecedents (restructuring the social environment; adding objects to the environment)
	75	Feedback and monitoring Antecedents (restructuring the social environment; adding objects to the environment)
	81	Goals and Planning Antecedents (adding objects to the environment)
	85	Shaping knowledge Antecedents (restructuring the social environment)
	86	Antecedents (restructuring the social environment)
	94*	Shaping knowledge Antecedents (adding objects to the environment)
	97	Shaping knowledge Antecedents (restructuring the social environment; adding objects to the environment)
	103	Shaping Knowledge Antecedents (adding objects to the environment) Goals and Planning Feedback and monitoring
	107	Antecedents (adding objects to the environment) Goals and Planning
	110	Antecedents (restructuring the social environment)
Person- and Family-	42*	Feedback and monitoring

Aspect of Care	References	BCT
Centred Care: Care Planning (n=12)		Antecedents (adding objects to the environment)
	45	Goals and planning Antecedents (restructuring the social environment)
	49	Goals and planning Antecedents (restructuring the social environment)
	51	Goals and Planning
	56*	Antecedents (adding objects to the environment)
	73	Antecedents (restructuring the social environment)
	96	Antecedents (restructuring the social environment)
	102	Antecedents (restructuring the social environment)
	111	Antecedents (restructuring the social environment) Goals and Planning
	112	Antecedents (restructuring the social environment) Feedback and monitoring
	116	Goals and Planning Antecedents (restructuring the social environment)
	117	Goals and Planning Antecedents (restructuring the social environment) Social support
Person- and Family Centred Care: Care Environment Programs (n=17)	34	Goals and Planning Antecedents (restructuring the social environment)
	36	Goals and planning Feedback and monitoring Antecedents (restructuring the physical and social environments)
	58	Feedback and monitoring (Self-monitoring of behavior) Antecedents (restructuring the social environment)
	59	Antecedents (restructuring the social environment; adding objects to the environment) Social support
	64	Shaping knowledge Natural consequences
	67	Social support Antecedents (restructuring the social environment)
	78	Shaping knowledge Antecedents (adding objects to the environment) Social support
	79	Antecedents (restructuring the social environment; adding objects to the environment)

Aspect of Care	References	BCT
		Goals and Planning
	87	Social Support Antecedents (Restructuring the social environment)
	92	Goals and Planning Antecedents (restructuring the social environment)
	99	Antecedents (restructuring the social environment)
	100	Antecedents (restructuring the physical and social environments; adding objects to the environment)
	101	Antecedents (restructuring the physical and social environments; adding objects to the environment)
	104	Goals and Planning Antecedents (restructuring the social environment; adding objects to the environment)
	108	Antecedents (restructuring the social environment)
	113	Shaping knowledge Antecedents (restructuring the social environment)
	115	Shaping knowledge Feedback and monitoring
Care Coordination (n=5)	38	Shaping knowledge Antecedents (adding objects to the environment)
	40	Shaping knowledge Antecedents (adding objects to the environment) Feedback and monitoring Natural consequences Goals and planning
	41	Shaping knowledge Antecedents (adding objects to the environment) Natural consequences Goals and planning
	43	Antecedents (adding objects to the environment) Regulation
	57	Shaping knowledge Identity
Effective Treatment (n=5)	70	Shaping knowledge Feedback and monitoring Repetition and Substitution Regulation
	83	Antecedents (restructuring the social environment; adding objects to the environment) Goals and planning Repetition and substitution Regulation
	89	Antecedents (adding objects to the environment) Feedback and monitoring

Aspect of Care	References	BCT
		Shaping knowledge
	106	Shaping knowledge Antecedents (restructuring the social environment; adding objects to the environment)
	109	Antecedents (restructuring the social environment) Social support Regulation

* Studies that included some information technology used by patients and/or families.

Overall, the use of antecedents was the most frequently identified category of BCT (n=76, 87.3%). This category includes: restructuring the physical environment; restructuring the social environment; avoidance/reducing exposure to cues for the behavior; distraction; adding objects to the environment and body changes (e.g. strength training).¹⁹ Antecedents can be used to “set the stage” for desired responses. Because of the frequency of identification of the category of antecedents, this category of BCT was further coded into the specific techniques employed. Adding objects to the environment was identified as an antecedent in a total of 48 (55.2%) studies. Examples of adding objects to promote patient participation in care included the use of instructional videos e.g.^{62, 99} and introduction of technologies such as tablets to share information.³¹ Fifteen (17.2%) of these studies simultaneously added objects in conjunction with restructuring the social environment. This is illustrated by Dykes et al.’s⁵⁵ multifaceted intervention involving a patient-centred care and engagement program and web-based technology, including a safety checklist and a messaging platform used by patients and care partners to view health information, participate in their care plan and communicate with care providers.

Studies that changed the social environment (n=41, 47.1%) to facilitate patient participation in care were classified as having employed the BCT of restructuring the social environment [BCT]. Following the BCT coding rules of Pesseau et al.²¹, we included in this category studies which described interventions in which someone new (patients, family member or provider) took on care, someone was added to take on new care responsibilities or someone was added to the team, or care was shifted

1
2
3 outside the team. An example of changes made to the social environment was the adoption of a new
4 model of care providing flexible family visiting, supporting carer involvement and improving
5
6 partnerships between carers and the health care team.⁵⁹
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10 Five studies (5.7%) were identified as making simultaneous changes to both the social and
11 physical environments. An instance of changing both the social and physical environment was reported
12 by Rise et al.¹⁰⁰, who established a new patient education center as one component of an intervention,
13 along with appointing staff who could be contacted by families. No studies were identified as
14 restructuring only the physical environment.
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22 Shaping knowledge was identified as a BCT in 33 studies (37.9%). This BCT is illustrated in the
23 study by Langer et al.⁸⁰ in which clinicians were brought together with patients and families in a
24 collaborative learning experience focused on developing patient-centred medical error disclosure
25 communication skills. A second example of shaping knowledge was the use of the PINK (Participate; Be
26 informed; Notice and be alert; Know what you can do) video⁴⁶ with the specific goal of educating
27 patients in the prevention of medical errors.
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36 Feedback and monitoring were identified in 20 studies (23.0%). An example is Coleman et al.'s
37 ⁴⁰Care Transition program, in which patients monitored and responded to changes in their health
38 conditions as a component of the intervention. Goals and planning were coded in 19 studies (21.8%). An
39 example of goals and planning involved goal setting meetings between the patient, family, and
40 multidisciplinary team.⁴³ Other categories of BCTs identified in the studies included: social support
41 (n=7; 8.0%); repetition and substitution (n=5; 5.7%); regulation (n=4; 4.6%); natural consequences (n=3;
42 3.4%); and comparison of behavior (n=2; 2.3%). The BCTs of association, identity and scheduled
43 consequences were identified in one study each. Categories of BCT not identified in any of the included
44 studies were reward and threat, self-belief and covert learning.
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3 In the majority of studies (n=69; 79.3%), the use of multiple categories of BCT as part of the
4 capacity-building intervention could be identified. In studies where only a single BCT was identified,
5 restructuring the social environment^{52, 73, 76, 86, 91, 96, 99, 101, 108, 110} occurred most frequently (n=10),
6 although adding objects to the environment^{33, 39, 53, 56, 60, 63}, and goals and planning^{48, 51} were also
7 employed as BCTs.
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15 **4.0 Discussion and Conclusion**

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17 This scoping review has identified seven aspects of care in which efforts to build capacity of
18 hospitalized patients to participate in care were reported: patient safety; care coordination; effective
19 treatment; bedside nursing hand-overs; communication between patients and providers; inpatient care
20 planning; and the overall care environment. Both large-scale (hospital-wide) and population- and unit-
21 specific interventions were reported. Descriptions of these interventions in the included studies
22 provided sufficient detail to allow for classification of the key BCTs utilized within each intervention. The
23 use of antecedents (e.g. adding objects to the environment or restructuring the social and/or physical
24 environment) was the most frequently identified BCT category across all included studies. In 60 per cent
25 of the studies, multiple BCTs could be identified.
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39 In keeping with the nature of a scoping review, the articles included in this scoping review were
40 heterogeneous in terms of the aspect of care addressed, aims and methodological rigor. This
41 heterogeneity limited our ability to draw conclusions about the effectiveness of the interventions.
42 Quality appraisal was not undertaken and, as previously identified, articles were limited to English
43 language only and did not include grey literature. Specific details of interventions were not always
44 provided in the publications and it is possible that some BCTs used could not be accurately identified by
45 the three reviewers who classified and achieved consensus on the BCTs identified. While our search
46 strategy was limited to MEDLINE, Embase and CINAHL, it would be helpful to consider the inclusion of
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3 additional databases in future reviews. Although we searched the Cochrane database and did not find
4 relevant systematic reviews, new reviews may be available in the future. As research addressing patient
5 participation in care becomes increasingly more sophisticated, future reviews may focus on specific
6 aspects of care such as safety for defined groups of patients.
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13 Reviews are increasingly seeking to identify the BCTs used in a range of interventions ^{e.g., 118-120} in
14 order to better understand the content of interventions and the underlying reasons for the outcomes
15 associated with interventions. Adding objects to the environment was identified as the most frequently
16 used BCT intervention in this scoping review, in keeping with the findings of Presseau et al. ²¹ Depending
17 on the nature of the publication and the intervention, more detailed descriptions of interventions were
18 available for some studies compared to others. Attempts to build capacity for patients to participate in
19 care are, at their core, social in nature, and particular care should be taken to describe how the social
20 environment facilitates performance of the desired behavior or creates barriers to behaviors excluding
21 patients or families from participation.
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34 Interventions aimed at building the capacity of hospitalized patients to participate more fully in
35 care require the use of complex interventions, especially as patient behavior cannot change
36 independently of provider behavior and health care system attributes. Genuine engagement of patients
37 in care will require a re-alignment of long-standing power imbalances between patients, providers and
38 the health care system, resulting in significant changes in behavior at many levels. ¹²¹ The participation
39 of a patient representative on this team examining the issue of patient participation proved to be
40 extremely helpful. This individual participated in all aspects of this review, from defining the research
41 question, screening and selection of included studies and data extraction. He provided key insights into
42 the interpretation of the results from the perspective of an end user of the health care system. This
43 individual reported that participation in this process gave him a sense of empowerment that he was
44 influencing the knowledge base of patient care. He also noted that the process provided him with
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3 knowledge to better critique the delivery of health services. The recent GRIPP2 reporting checklist on
4 improving the reporting of patient and public involvement in research ²⁶ provides important guidance on
5 this issue. We would recommend that future studies include patient focus groups as a means of
6 expanding patient input.
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13 The rapidly evolving interest in developing interventions promoting the participation of
14 hospitalized patients in care was demonstrated by the additional 660 articles that were published over
15 the eight-month period between the time of the initial search and the search update. Given the growing
16 corpus of research, this review provides an important synthesis of what has been reported to build the
17 capacity of hospitalized patients to participate in care. This review aimed also to classify the “active
18 ingredients” underpinning the interventions by using the BCT Taxonomy. ¹⁹ The findings generated
19 through this synthesis will provide an evidentiary basis for the development of, and future research
20 related to, tailored approaches to building patient capacity to participate in care.
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30 31 Figure Legend

32 33 34 Figure 1: Prisma Screening Flowchart

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42
43
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47 influence, their work.
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3 Author Contributions: DG, EH, MS and TR conceptualized the study. EW conducted the literature search.

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5 DG coordinated the project and is the guarantor. MM, LN, MS, EH, TR, CH, EP and DG screened the
6
7 studies and contributed to the interpretation of findings. DG, MM and LN extracted the data. DG drafted
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9 and all authors critically reviewed and approved the revised manuscript.
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13 Data sharing statement: All publications in this review have been duly referenced and are publicly
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15 available.
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References

1. Groene O. Patient-centredness and quality improvement efforts in hospitals: rationale, measurement, implementation. *Int J Qual Health Care* 2011;23:531-537.
2. Lombarts MJ, Rupp I, Vallejo P, Sunol R, Klazinga NS. Application of quality improvement strategies in 389 European hospitals: results of the MARQuIS Project. *BMJ Qual Saf* 2008;18(Suppl1):i28-i37.
3. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff* 2013;32(2):223-231.
4. Clancy CM. Patient engagement in health care. *Health Serv Res* 2011;46:389-393.
5. World Health Organization. Patient Engagement: Technical Series on Safer Primary Care 2016. Available at <http://apps.who.int/iris/bitstream/handle/10665/252269/9789241511629-eng.pdf;jsessionid=2D38D96403E594B7509C1F6079358A6A?sequence=1>.
6. Hibbard JH, Mahoney ER, Stock R et al. Do increases in patient activation result in improved self management behaviors? *Health Serv Res* 2007;42:1443-63.
7. Mosen DM, Schmittiel J, Hibbard et al. Is patient activation associated with outcomes of care for adults with chronic conditions? *J Ambul Care Manage* 2007;30:21-9.
8. Weingart SN, Zhu J, Chiapetta L et al. Hospitalized patient participation and its impact on quality of care and patient safety. *Int J Qual Health Care* 2011;23:269-77.
9. Epstein RM, Franks P, Shields CG et al. Patient-centred communication and diagnostic testing. *Ann Fam Med* 2005;3:415-21.
10. Bertakis KD, Azari R. Patient-centred care is associated with decreased health care utilization. *J Am Board Fam Med* 2011;24:229-39.
11. Charmel P, Frampton S. Building the business case for patient-centred care. *Healthc Financ Manage* 2008;62;80-5.

- 1
2
3 12. Aronson PL, Yau J, Helfaer MA et al. Impact of family presence during pediatric intensive care rounds
4 on the family and medical team *Pediatrics* 2009;24:1119-25.
5
6
7 13. Balik B, Conway J, Zipperer L, Watson J. Achieving an exceptional patients and family experience of
8 inpatient hospital care. IHI Innovation Series white paper. Cambridge, MASS: Institute for Healthcare
9 Improvement, 2011. Elements of hospital-based patient- and family-centred care
10
11
12 14. Gausvik C, Lautar A, Miller L, et al. Structured nursing communication on interdisciplinary acute care
13 teams improves perceptions of safety, efficiency, understanding of care plans and team work as well as
14 job satisfaction. *J Multidisc Healthcare* 2015;8:337.
15
16
17 15. Batalden M, Batalden P, Margolis P, Armstrong G, Opipari-Arrigan L, Hartung, H. Coproduction of
18 healthcare service. *BMJ Qual Saf* 2016; 25: 509-17. doi: 10.1136/bmjqs-2015-004315.
19
20
21 16. Gagliardi AR, Legare F, Brouwers MC, Webster F, Badley E, Straus S. Patient-mediated knowledge
22 translation (PKT) interventions for clinical encounters: a systematic review. *Implem Sci* 2016;11:26.17.
23
24
25 17. Herrin J, Harris KG, Kenward K, Hines S, Joshi MS, Frosch DL. Patient and family engagement: a
26 survey of US hospitals. *BMJ Qual Saf* 2015;0: 1-8.
27
28
29 18. Agency for Healthcare Research and Quality. 2015 National healthcare quality and disparities report
30 and 5th anniversary update on the National Quality Strategy: Priorities of the National Quality Strategy.
31 Available at <https://www.ahrq.gov/research/findings/nhqdr/nhqdr15/priorities.html>.
32
33
34 19. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W et al. The Behavior Change
35 Technique Taxonomy (v1) of 93 hierarchically clustered techniques: Building an international consensus
36 for the reporting of behavior change interventions. *Ann Behav Med* 2013;46:81-92.
37
38
39 20. National Institute for Health and Care Excellence (NICE). Behaviour change: individual approaches.
40 <https://www.nice.org.uk/guidance/ph49/chapter/7-glossary>.
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 21. Pesseau J, Ivers NM, Newham JJ, Knittle K, Danko KJ, Grimshaw JM. Using a behavior change
4 techniques taxonomy to identify active ingredients within trials of implementation interventions for
5 diabetes care. *Implem Sci* 2015;10:55
6
7
8
9
10 22. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *Int J Soc Res Meth*
11 2005;8:19-32.
12
13
14 23. Goodridge D, Henry C, Watson E, McDonald M, New L, Harrison EL, Scharf M, Penz E, Campbell S,
15 Rotter T. Structured approaches to promote patient and family engagement in treatment in acute care
16 hospital settings: protocol for a systematic scoping review. *Syst Rev* 2018;7:35.
17
18
19 24. Colquhoun HL, Levac D, O'Brien KK, Straus S, Tricco AC, Perrier , Kastner M, Moher D. Scoping
20 reviews: time for clarity in definition, methods and reporting. *J Clin Epidemiol* 2014;67:1291-4.
21
22
23 25. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology, *Implem Sci*
24 2010;5:69.
25
26
27 26. Daudt HML, van Mossel C, Scott SJ. Enhancing the scoping study methodology: a large, inter-
28 professional team's experience with Arksey and O'Malley's framework. *BMC Med Res Methodol*
29 2013;13:48.
30
31
32 27. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping
33 Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med* 2018;169:467–473. doi:
34 10.7326/M18-0850.
35
36
37 28. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. GRIPP2 reporting checklists:
38 tools to improve reporting of patient and public involvement in research. *BMJ* 2017;358:j3453.
39
40
41 29. Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia. Available
42 at <http://www.covidence.org>.
43
44
45 30. Anthony R, Miranda F, Mawji Z, Cerimele R, Davis R, Lawrence S. John M. Eisenberg Patient Safety
46 Awards. The LVHNN patient safety video: patients as partners in safe care delivery. *Joint Comm J Qual*
47 *Saf* 2003;29:640-645.
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 31. Ayana M, Pound P, Ebrahim S. The views of therapists on the use of a patient-held record in the care
4 of stroke patients, *Clin Rehab* 1998;12:328-337.
5
6
7 32. Baird SK, Turbin LB. Condition Concern: an innovative response system for enhancing hospitalized
8 patient care and safety. *J Nurs Care Qual* 2011;26(3):199-207.
9
10
11 33. Baysari MT, Adams K, Lehnbohm EC, Westbrook JI, Day RO. iPad use at the bedside: a tool for
12 engaging patients in care processes during ward rounds? *Int Med J* 2014;44(10):987-990.
13
14
15 34. Berger JL. Incorporation of the tidal model into the interdisciplinary plan of care – a program quality
16 improvement project. *J Psychiatr Men Health Nurs* 2006;12:464-467.
17
18
19 35. Black P, Boore HRP, Parahoo K. The effect of nurse-facilitated family participation in the
20 psychological care of the critically ill patient. *J Adv Nurs* 2011; 76(5):1091-1101.
21
22
23 36. Boltz M, Chippendale T, Resnick B, Galvin JE. Testing family-centred, function-focused care in
24 hospitalized persons with dementia. *Neurodegener Dis Manage* 2015;5(3):203-215.
25
26
27 37. Bradley S, Mott S. Adopting a patient-centred approach: an investigation into the introduction of
28 bedside hand-over to three rural hospitals. *J Clin Nurs* 2014;23:1927-1936.
29
30
31 38. Bull MJ, Hansen HE, Gross CR. A professional-patient partnership model of discharge planning with
32 elders hospitalized with heart failure. *Appl Nurs Res* 2000;13:19-28.
33
34
35 39. Buning AW, Klopotoska JE, Duyvendak M, Engelen LJLP, Arts J. Patient empowerment through the
36 provision of a mobile application for medication reconciliation: a proof of concept study. *BMC*
37 *Innovations* 2016;2:152-157.
38
39
40
41 40. Coleman EA, Parry C, Chalmers S, Min SJ. The care transitions intervention: results of a randomized
42 controlled trial. *Arch Int Med* 2006;166:1822-9.
43
44
45 41. Coleman EA, Smith JD, Parry C, Chalmers S, Min SJ. Preparing patients and caregivers to participate
46 in care delivered across settings: The care transitions intervention. *J Am Ger Soc* 2004;52:1817-1825.
47
48
49 42. Cook DJ, Manning DM, Holland DE, Prinsen SK, Rudzik SD, Roger VL, Deschamps C. Patient
50 engagement and self-reported outcomes in surgical recovery: effectiveness of an e-health platform. *J*
51 *Am Coll Surg* 2013;217:648-655.
52
53
54
55
56
57
58
59
60

- 1
2
3 43. Cordasco KM, Asch SM, Bell DS, Guterman JJ, Gross-Schulman S, Ramer L et al. A low-literacy
4 education tool for safety-net hospital patients. *Am J Prev Med* 2009;37:S209-S216.
5
6
7 44. Dalal AK, Dykes PC, Collins S, Lehmann LS, Ohashi Km Rozenblum R et al. A web based, patient-
8 centred toolkit to engage patients and caregivers in the acute-care setting: a preliminary evaluation. *J*
9 *Am Med Inform Assoc* 2016;23:80-87.
10
11
12 45. Dalton C, Farrell R, De Souza A, Wujanto E, McKenna-Slade A, Thompson S et al. Patients inclusion in
13 goal setting during early inpatient rehabilitation after acquired brain injury. *Clin Rehab* 2012;26:165-173.
14
15
16 46. Davis RE, Pinto A, Sevdalis N, Vincent C, Massey R, Darzi A. Patients' and professionals' attitudes
17 towards the PINK patient safety video. *J Eval Clin Pract* 2012;18:848-853
18
19
20 47. Davis RE, Sevdalis N, Pinto A, Darzi A, Vincent CA. Patients' attitudes towards patient involvement in
21 safety interventions: results of two exploratory studies. *Health Exp* 2013;16:163-176.
22
23
24 48. D'Cruz K, Unsworth C, Roberts K, Morarty J, Turner-Stokes L, Wellington-Boyd A et al. Engaging
25 patients with moderate to severe acquired brain injury in goal setting. *Int J Ther Rehab* 2016;23:20-31.
26
27
28 49. Dev R, Coulson L, Del Fabbro E, Palla SL, Yennurajalingam S, Rhondali W, Bruera E. A prospective
29 study of family conferences: Effects of patient presence on emotional expression and end-of-life
30 discussions. *J Pain Sympt Manag* 2013;46:536-545.
31
32
33 50. Dijkstra R, Braspenning J, Grol R. Empowering patients: how to implement a diabetes passport in
34 hospital care. *Pat Ed Couns* 2002;47:173-177.
35
36
37 51. Donnelly SM, Carter-Anad J, Cahill S, Gilligan R, Mehigan B, O'Neill D. Multiprofessional views on
38 older patients' participating in care planning meetings in a hospital context. *Practice Soc Work Act*
39 2013;25;121-138.
40
41
42 52. Doyle CJ, Post H, Burney RE, Maino J, Keefe M, Rhee KJ et al. Family participation during
43 resuscitation: an option. *Ann Emerg Med* 1987;16:673-675.
44
45
46 53. M. Duckworth, E. Leung, T. Fuller, J. Espares, B. Couture, F. Chang, A.C. Businger, S. Collings, A. Dalal,
47 A. Fladger, J.L. Schnipper, K.O. Schnook, D.W. Bates, P.C. Dykes. Nurse, patient and care partner
48 perceptions of a personalized safety plan screensaver. *J. Gerontol. Nurs* (2017) 43:15-22.
49
50
51 54. Duncan C. An exploratory study of patients' feeling about asking healthcare professionals to wash
52 their hands. *J Ren Care* 2007;33:30-34.
53
54
55
56
57
58
59
60

- 1
2
3 55. Dykes PC, Rozenblum R, Dalal A, Massaro A, Chang F, Clements M, et al. Prospective evaluation of a
4 multifaceted intervention to improve outcomes in intensive care: The Promoting Respect and Ongoing
5 Safety through Patient Engagement Community and Technology Study. *Crit Care Med* 2017; 5:e806-
6 e813.
7
8
9
10 56. Dykes PC, Stade D, Chang F, Dalal A, Getty G, Kandala R et al. Participatory design and development
11 of a patient-centred toolkit to engage hospitalized patients and their care partners in their plan of care.
12 *AMIA Symposium* 2014:486-495.
13
14
15 57. Dystad DN, Storm M. Interprofessional simulation to improve patient participation in transitional
16 care. *Scand J Car Sci* 2017;31:273-284.
17
18
19 58. Ellegaard T, Bliksted V, Lomborg K, Mehlsen M. Use of patient-controlled psychiatric hospital
20 admissions: patients' perspective. *Nord J Psychiatry* 2017;71:370-77.
21
22
23 59. Ewart L, Moore J, Gibbs C, Crozier K. Patient- and family-centred care on an acute adult cardiac ward.
24 *Brit J Nurs* 2013;23:213-218.
25
26
27 60. Fredericks JE, Bunting RF. Implementation of a patient-friendly medication schedule to improve
28 patient safety within a healthcare system. *J Healthcare Risk Manag* 2010;29:22-27.
29
30
31 61. Furness ND, Bradford OJ, Paterson MP. Tables in trauma: mobile computing platforms to improve
32 patients understanding and experience. *Orthoped* 2013;36:205-208.
33
34
35 62. Gillespie BM, Chaboyer W, Sykes M, O'Brien J, Brandis S. Development and pilot-testing of a patient-
36 participatory pressure ulcer prevention care bundle. *J Nurs Care Qual* 2014;29:74-82.
37
38
39 63. Gill SD, Redden-Hoare J, Dunning TL, Hughes AJ, Dolley PJ. Health services should collect feedback
40 from inpatients at the point of service: opinions from patients and staff in acute and subacute facilities.
41 *Int J Qual Healthc* 2015;27:507-512.
42
43
44 64. Gillis C, Gill M, Marlett N, Mackean G, Germann K, Gilmour K et al. Patients as partners in Enhanced
45 Recovery after Surgery: a qualitative patient-led study. *BMJ Open* 2017;7;no pagination.
46
47
48 65. Greenhouse PK, Kuzminsky B, Martin SC, Merryman T. Emergency calling a condition h(elp): one
49 facility gives patients and families the ability to summon a rapid response team. *Am J Nurs* 2006;106:63-
50 66.
51
52
53
54
55
56
57
58
59
60

- 1
2
3 66. Greysen SR, Khanna RR, Jacolbia R, Lee HM, Auerbach AD. Tablet computers for hospitalized
4 patients: a pilot study to improve patient engagement. *J Hosp Med* 2014;9:396-399.
5
6
7 67. Grieco AJ, Garnett SA, Glassman KS, Valoon PL, McClure ML. New York University Medical Center's
8 Cooperative Care Unit: Patient education and family participation during hospitalization – the first ten
9 years. *Pat Ed Couns* 1990;15:3-15.
10
11
12 68. Hamann J, Mendel R, Meier A, Asani F, Pausch E, et al. "How to Speak to your Psychiatrist": Shared
13 decision-making training for patients with schizophrenia. *Psych Serv* 2011;62:1218-1221.
14
15
16 69. Hill AM, McPhail SM, Francis-Cload-J, Waldron N, Etherton-Beer C, Flicker L, et al. Educators'
17 perspectives about how older patients can engage in a falls prevention education programme: a
18 qualitative process outcome. *BMJ Open* 2015;5(12)(no pagination)
19
20
21 70. Hirano Y, Maeshima S, Osawa, Nishio D, Takeda K, Baba M et al. The effect of voluntary training with
22 family participation on early home discharge in patients with severe stroke at a convalescent
23 rehabilitation hospital. *Eur Neurol* 2012;68:221-228..
24
25
26 71. Huffines M, Johnson KL, Naranjo LS, Lissauer ME, Fishel MA, D'Angelo SM. Participation in decision-
27 making in an intensive care unit. *Crit Care Nurs* 2013;33:56-69.
28
29
30 72. Ivarsson B, Larsson S, Luhrs C, Sjoberg T. extended written pre-operative information about possible
31 complications at cardiac surgery – do patients want to know? *Eur J Cardio-Thorac Surg* 2005;28:407-14.
32
33
34 73. Jacobowski NL, Girard TD, Mulder JA, Ely EW. Communication in critical care: family rounds in the
35 intensive care units. *Am J Crit Care* 2010;19:421-430.
36
37
38 74. Jangland E, Carlsson M, Lundgren E, Gunningberg L. The impact of an intervention to improve
39 patient participation in a surgical care unit: a quasi-experimental study. *Int J Nurs Stud* 2012;49:528-538.
40
41
42 75. Jangland E, Gunningberg L. Improving patient participation in a challenging context: a 2-year
43 evaluation study of an implementation project. *J Nurs Manag* 2017;25:266-275.
44
45
46 76. Jeffs L, Beswick S, Acott A, Simpson E, Cardoso R, Campbell H et al., Patients' views on bedside
47 handover. *J Nurs Care Qual* 2014;29:149-154.
48
49
50 77. Kutty S, Weil S. "Your health care – be involved": the evaluation of a provincial safety tips initiative.
51 *Healthc Quar* 2006;9:102-107.
52
53
54
55
56
57
58
59
60

- 1
2
3 78. Laitinen-Junkkari P, Merilainen P, Sinkkonen S. Informal caregivers' participation in elderly-patient
4 care: an interrupted time series study. *Int J Nurs Pract* 2001;7:199-213.
5
6
7 79. Lakeman R. Practice standards to improve the quality of family and carer participation in adult
8 mental health: an overview and evaluation. *Int J Ment Health Nurs* 2008;17:44-56.
9
10
11 80. Langer T, Martinez W, Browning D, Varrin P, Sarnoff Lee B, Bell SK. Patients as teachers in patient
12 safety: a new interprofessional educational model for collaborative learning about medical error
13 disclosure and prevention. *J Gen Int Med* 2015;30:S504.
14
15
16
17 81. Lankarani-Fard A, Knapp H, Lorenz KA, Golden JF, Taylor A, Feld JE, et al. Feasibility of discussing end-
18 of-life goals with inpatients using a structured, conversational approach: the go-wish care game. *J Pain*
19 *Sympt Manag* 2010;39:637-43.
20
21
22
23 82. Lawton R, O'Hara JK, Sheard L, Armitage G, Cocks K, Buckley H et al. Can patient involvement
24 improve patient safety? A cluster randomized control trial of the Patient Reporting and Action for a Safe
25 Environment (PRASE) intervention. *BMJ Qual Saf* 2017;26:622-631.
26
27
28
29 83. Lean M, Leavey G, Killaspy H, Green N, Harrison I, Cook S et al. Barriers to the sustainability of an
30 interventions designed to improve patient engagement within NHS mental health rehabilitation units: a
31 qualitative study nested within a randomized controlled trial. *BMC Psychiat* 2015; 15: (no pagination)
32
33
34
35 84. Lent V, Eckstein EC, Cameron AS, Budavich R, Eckstein BC, Donskey CJ. Evaluation of patient
36 participation in a patient empowerment initiative to improve hand hygiene practices in a Veterans
37 Affairs medical center. *Am J Inf Contr* 2009;37:117-120.
38
39
40
41 85. Leske JS, McAndrew NS, Brasel KJ, Feetham S. Family presence during resuscitation after trauma. *J*
42 *Trauma Nurse* 2017;24;85-96.
43
44
45
46 86. Lindberg E, Persson E, Horberg U, Ekeburgh M. Older patients' participation in team meetings – a
47 phenomenological study from the nurses' perspective. *Int J Qual Stud Health Well-being*
48 2013;8;10.3402/qhw.v8i0.21908
49
50
51
52 87. Livingston JD, Nijdam-Jones A, Lapsley S, Calderwood C, Brink J. Supporting recovery by improving
53 patient engagement in a forensic mental health hospital: results from a demonstration project. *J Am*
54 *Psychiatr Nurs Assoc* 2013;19:132-145.
55
56
57
58
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60

- 1
2
3 88. Louch G, O'Hara J, Mohammed MA. A qualitative formative evaluation of a patient-centred patient
4 safety intervention delivered in collaboration with hospital volunteers. *Health Expect* 2017;15:15.
5
6
7 89. Martinez-Velilla N, Guerrues-irisarri M, Ibanez-Beroia B, Gil-Cabanas J, Richarte-Carcia A, Idoate-
8 Saralegui F et al. An exercise program with patients' involvement and family support can modify the
9 cognitive and affective trajectory of acutely hospitalized older medical patients: a pilot study. *Aging Clin*
10 *Exp Res* 2016;28:483-490.
11
12
13
14 90. McGuckin M, Waterman R, Storr J, Bowler ICJW, Ashby M, Topley K et al. Evaluation of a patient-
15 empowering hand hygiene program in the UK *J Hosp Inf* 2001;48:222-227.
16
17
18 91. McMurray A, Chaboyer W, Wallis M, Johnson J, Gehrke T. Patients perspectives of bedside nursing
19 handover. *Collegian* 2011;18:19-26.
20
21
22 92. Nyborg I, Kvigne K, Danbolt LJ, Kirkevold M. Ambiguous participation in older hospitalized patients:
23 gaining influence through active and passive approaches – a qualitative study. *BMC Nurs*;15:50.
24
25
26 93. Odell M, Gerber K, Gager M. Call 4 concern: patient and relative activated critical care outreach. *Br J*
27 *Nurs* 2010;19:1390-1395.
28
29
30 94. O'Leary KJ, Lohman ME, Culver E, Killarney A, Smith GR, Liebovitz DM. The effect of tablet computers
31 with a mobile patient portal application on hospitalized patients' knowledge and activation. *J Am Med*
32 *Inform Assoc* 2016;23:159-165.
33
34
35 95. Olso TM, Gudde CB, Moljord IEO, Evensen GH, Antonsen DO et al. More than just a bed: mental
36 health service users' experiences of self-referral admission. *Int j Ment Health Sys* 2016;10: (no
37 pagination).
38
39
40 96. Paradis E, Leslie M, Gropper MA. Interprofessional rhetoric and operational realities: an
41 ethnographic study of rounds in four intensive care units. *Adv Health Sci Educ* 2016;21:735-48.
42
43
44 97. Pegg PO, Auerbach SM, Seel RT, Buenaver LF, Keisler DJ, Plybon LE. The impact of patient-centred
45 information on patients' treatment satisfaction and outcomes in traumatic brain injury rehabilitation.
46 *Rehab Psychol* 2005;50:366-374.
47
48
49 98. Pinto A, Vincent C, Darzi A, Davis R. A qualitative exploration of patients' attitudes towards the
50 "Participate Inform Notice Know' (PINK) patient safety video *Int J Qual Health Care* 2013; 25:29-34.
51
52
53
54
55
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60

- 1
2
3 99. Pomey MP, Ghadiri DP, Karazivan P, Fernandez N, Clavel N. Patients as partners: a qualitative study
4 of patients' engagement in their health care. PLoS ONE 2015;10: (no pagination) e0122499.
5
6
7 100. Rise MB, Grimstad H, Solbjor M, Steinsbekk A. Effect of an institutional development plan for user
8 participation on professionals' knowledge, practice and attitudes. A controlled study. BMS Health Serv
9 Res 2011;11:296.
10
11
12 101. Rise MB, Steinsbekk A. Does implementing a development plan for user participation in a mental
13 health hospital change patients' experience? A non-randomized controlled study. Health Expect
14 2105;18:809-825.
15
16
17 102. Rotman-Pikielny P, Rabin B, Amoyal S, Mushkat Y, Zissin R, Levy Y. Participation of family members
18 in ward rounds: attitude of medical staff, patients and relatives. Pat Ed Couns 2007;65:166-170.
19
20
21 103. Ruland CM. Decision support for patient preference-based care planning: effects on nursing care
22 and patient outcomes. J Am Med Inform Assoc 1999;6:304-12.
23
24
25 104. Ruland CM. Clinicians' use of a palm-top based system to elicit patient preferences at the bedside:
26 a feasible technique to improve patient outcomes. Proc AMIA 2000;739-43.
27
28
29 105. Sand-Jecklin K, Sherman J. Incorporating bedside report into nursing handoff: evaluation of change
30 in practice. J Nurs Care Qual 2013;28:186-194.
31
32
33 106. See MTA, Chan WCS, Huggan PJ, Tay YK, Liaw SY. Effectiveness of a patient education intervention
34 in enhancing the self-efficacy of hospitalized patients to recognize and report acute deteriorating
35 conditions. Pat Ed Coun 2014;97:122-127.
36
37
38 107. Sehgal NL, Green A, Vidyarthi AR, Blegen MA, Wachter RM. Patient whiteboards as a
39 communication tool in the hospital setting: a survey of practices and recommendations. J Hosp Med
40 2010;5:234-9.
41
42
43 108. Shulkin D, O'Keefe T, Visoni D, Robinson A, Rooke AS, Neigher W. Eliminating visiting hour
44 restrictions in hospital. J Healthcare Qual 2014;26:54-57.
45
46
47 109. Skolasky RL, Maggard AM, Li D, Riley LH, Wegener ST. Health behavior change counseling in surgery
48 for degenerative lumbar stenosis. Part II: Activation mediates the effects of health behavior change
49 counseling on rehabilitation engagement.
50
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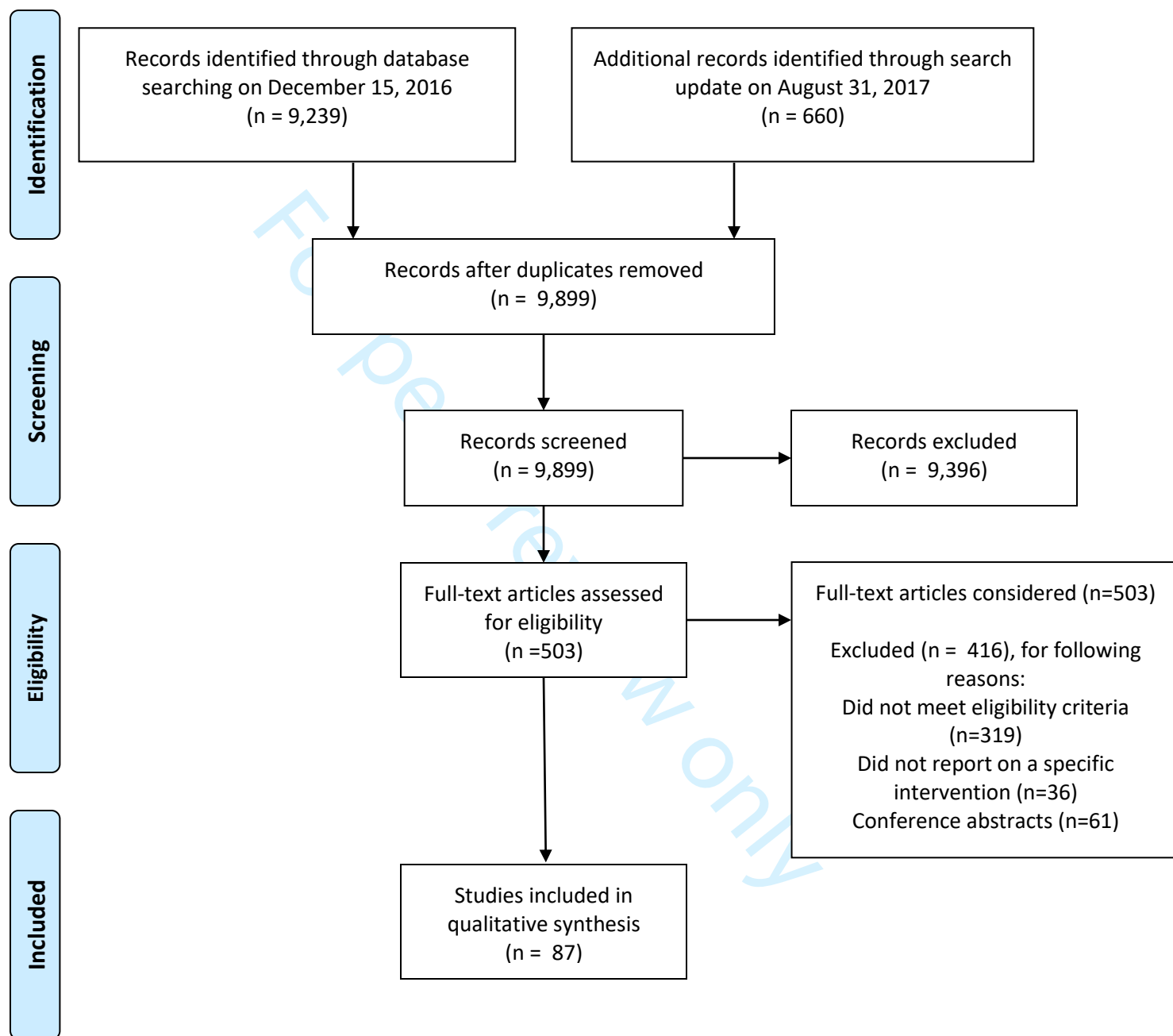
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2
3 110. Stein EG, Furedy RL, Simonton MJ, Neuffer CH. Patient access to medical records on a psychiatric
4 inpatient unit *Am J Psychiatr* 1979;136:327-9.
5
6
7 111. Swenne CL, Skytt B. The ward round – patient experiences and barriers to participation. *Scand J Car*
8 *Sci* 2014;28: (8p)
9
10
11 112. Timonen L, Sihvonen M. Patient participation in bedside reporting on surgical wards. *J Clin Nurs*
12 2000;9:542-548.
13
14
15 113. Trummer UF, Mueller UO, Nowak P, Stidl T, Pelikan JM. Does physician-patients communication
16 that aims at empowering patients improve clinical outcome? A case study. *Pat Ed Couns* 2006;61:299-
17 306.
18
19
20
21 114. Turner J, Gardner B, Staples T, Chapman J. Medicines with respect (part two): Implementation and
22 evaluation of a medication management initiative in acute in-patient settings. *Ment Health Nurs*
23 2008;28:12-16.
24
25
26
27 115. Van Gaal BGI, Schoonhoven L, Mintjes JAJ, Borm GF, Hulscher MEJL, Defloor T et al. Fewer adverse
28 events as a result of the SAFE or SORRY? Programme in hospitals and nursing homes. Part i: primary
29 outcome of a cluster randomized trial. *Int J Nurs Stud* 2011;49:1040-1048.
30
31
32
33 116. Wressle E, Eeg-Olofsson A-M, Marcusson J, Henriksson C. Improved client participation in the
34 rehabilitation process using a client-centred goal formulation structure. *J Rehabil Med* 2002;34:5-11.
35
36
37 117. CA Young, Manmathan GP, Ward, JC. Perceptions of goal-setting in a neurological rehabilitation
38 unit: a qualitative study of patients, carers and staff. *J Rehabil Med* 2008;40:190-4.
39
40
41 118. L. Hollywood, D. Surgenor, M. Reicks, L. McGowan, F. Lavelle, M. Spence, M. Raats, A. McCloat, E.
42 Mooney, M. Caraher, M. Dean, Identification of behavior change technique applied in interventions to
43 improve cooking skills and food skills among adults. *Crit. Rev. Food. Sci. Nutr.* 7 (2017) 1-14.
44
45 119. L. Kahwati, M. Viswanathan, Golin C.E., H. Kane, M. Lewis, S. Jacobs S. Identifying configurations of
46 behavior change techniques in effective medication adherence interventions: a qualitative comparative
47 analysis. *System Rev.* 5 (2016) 83.
48
49
50
51 120. Soltani H, Arden MA, Duxbury AMS, Fair FJ. An analysis of behavior change technique used in a
52 sample of gestational weight management trial. *J Pregnancy* 2016;Article ID 1085916.
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121. Goodridge D, Isinger T, Rotter T. Patient family advisors' perspectives on engagement in health-care quality improvement initiatives: power and partnership. Health Exp 2017; 21:379-386.

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PRISMA 2009 Flow Diagram



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(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

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Supplementary File 1: Search Strategy - Comprehensive Medline Strategy

Database(s): Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

Search Strategy:

#	Searches	Results
1	acute care.mp. hospitals/ or exp hospitals, community/ or exp hospitals, general/ or exp hospitals, group practice/ or exp hospitals, high-volume/ or exp hospitals, low-volume/ or exp hospitals,	17713
2	private/ or exp hospitals, public/ or exp hospitals, rural/ or exp hospitals, satellite/ or exp hospitals, teaching/ or exp hospitals, urban/ or secondary care centers/ or tertiary care centers/	197791
3	hospital*.mp.	1356031
4	inpatients/ (in-patient? or inpatient?).mp. [mp=title, abstract, original title, name of substance word,	17400
5	subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	1503794
6	or/1-5	2652901
7	patient participation/	22552
8	caregivers/	29583

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19	14	((carer? or caregiver? or client? or consumer? or families or family or patient? or stakeholder? or user?) adj2 (empower* or engage* or participat*)).ab. /freq=2
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30	16	((carer? or caregiver? or client? or consumer? or families or family or patient? or stakeholder? or user?) adj involve*).ab. /freq=2
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12	24 remove duplicates from 23	4773
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Supplementary File 2. Scoping Review Data Extraction Sheet

Primary author/organization:		
Title of article:		
Source of publication (Name of journal or report):		
Year of publication:		
Reviewer initials:		
Country		
Overall Aim and Purpose of the Study		
Focus of Patient Engagement Program		
Describe the Intervention		
Duration of Program		
Theoretical Framework (Identify and describe, if present)		
Study Design (Quantitative)	Case Series	
	Cross-Sectional (Pre- and post)	
	Case-control	
	Retrospective Cohort	
	Prospective Cohort	
	RCT	
	Other	
Study Design (Qualitative)	Basic Interpretive	
	Phenomenological	
	Grounded Theory	
	Ethnographic	
	Case Study	
	Other	
Study Design (Mixed Methods)	QUAL core QUAN core Sequence	
	Instruments Used	

1	Non-Research Document	Describe type	
2			
3	Type of Hospital	Teaching	
4		Community	
5		Rehabilitation	
6		Psychiatric/Mental Health	
7		Other	
8	Type of Unit		
9	Participants	Number of participants	
10		Type of Participants	Patient Family Member Care Provider Other
11		Medical diagnoses	
12		Age range	
13		Sex (%)	
14		Inclusion criteria	
15		Exclusion criteria	
16	Results	Patient outcomes	
17		Health care provider outcomes	
18		Health system & effectiveness outcomes	
19		Funder outcomes	
20	Comments		

Supplementary File 3. Summary of Included Articles

Citation	Country	System Improvement	Description of Intervention	Study Design, Participants	Findings	BCT
30	US	Patient Safety	Patient video addressing: treatment plan, med safety, falls, surgical site identification, hand-washing and discharge planning.	Survey of 217 patients	Increased comfort in talking to providers about concerns Self-rated knowledge of patient safety improved	Shaping knowledge Antecedents (adding objects to the environment)
31	UK	PFCC: Bedside Nursing Handovers	Patient-held booklet for staff to record information on management. Aim was to facilitate communication and involve patients in rehabilitation care.	Six focus groups of therapists (n=25) Content analysis	Supportive, but questioned feasibility for both patients and staff. Ownership does not guarantee confidence needed to encourage dialogue. Differences in philosophies of care between therapists.	Shaping knowledge Antecedents (adding objects to the environment)
32	US	Patient Safety	Method to report unattended care concerns (call hospital emergency alert system). Aim to provide a practical safety net. Policies, education, audit tool signage for program.	Data on concern reports gathered over 6 months.	69 calls (3 x greater than a similar program). Key issues: plan of care; pain management; coordination of care; response to call light; other; not valid concern and dissatisfied with staff.	Antecedents (Restructuring the physical and social environment; adding objects to the environment)
33	Hospital AU	PFCC: Communication	iPad to share information with patient during ward rounds	10 senior doctors shadowed on rounds with 525	iPads were not used to share information. Patients did not believe	Antecedents (Adding objects to the environment)

				patients over 77 hours. 7 doctors interviewed and 180 patients completed survey.	iPads impacted on engagement.	
34	CAN	PFCC: Care environments	Tidal model focuses on engaging person and client-centred care in psychiatry.	46 patients and 17 staff completed short questionnaires	IPC associated with client and caregiver satisfaction (no validated instruments used)	Goals and Planning Antecedents (Restructuring the social environment)
35	UK	PFCC: Communication	Family education on delirium and psychological care via booklet – nurses promote family access to patient and encouraged interaction in ICU.	Comparative time series of 170 critically ill patients and families – 83 controls, 87 intervention	No reduction in delirium, but patients demonstrated better psychological recovery and well-being at 4, 8, and 12 weeks	Shaping knowledge Social Support
36	US	PFCC: Care environments	Create enabling environment that promoted medical patient engagement in functional recovery. Environmental and Policy Evaluation; Staff education; Ongoing training and motivation of nursing staff; FamCare. Individualized goals and mentoring.	Comparative repeated measures design; 44 dyads on intervention units and 42 dyads on control	Intervention group demonstrated better ADL and walking, less severity/duration of delirium and readmission, no significant difference in gait/balance. Families showed increased preparedness for caregiving and less anxiety but no differences in depression, strain or mutuality.	Goals and planning Feedback and monitoring Antecedents (Restructuring the physical and social environments)

37	AU	PFCC: Bedside nursing hand-over	Nurse-to-nurse bedside handover in rural hospitals.	Mixed methods, pretest, post-test approach using quasi-experimental and ethnographic elements. Ethnographic interviewing. Staff perceptions on scale and by interview. 9 inpatients and 48 nursing staff.	Patients preferred bedside hand-over (know who is caring for them, social aspects and inclusion). Staff believed patient involvement had increased.	Antecedents Restructuring the physical and social environments Scheduled consequences
38	US	Care Coordination	Educational program for nurses and social workers; cardiac patients and caregivers completed discharge planning survey and viewed video; given structured questions; given medication list and brochure on accessing community services	Before and after non-equivalent control group design with 158 dyads and 2 month follow-up in two hospitals	Patients felt more prepared to manage care, reported more continuity of information, felt they were in better health, reduced LOS when re-admitted	Shaping knowledge Antecedents (adding objects to the environment)
39	The Netherlands	Patient safety	Patient-operated mobile app MyMedication to assist with medication reconciliation. Patients create their own medication lists of the medications they actually use. Barcodes can be scanned and matched	Convenience sample of 17 elective surgery patients. AT admission, medication list in app was compared with	The use of the app shows potential as a tool to improve patient safety and reduce healthcare costs.	Antecedents (adding objects to the environment)

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			with database included in the app.	list compiled by a pharmacy practitioner and discrepancies quantified.		
40	US	Care Coordination	Transition coach for medical patients. 4 pillars: assistance with medication self-management; patient-centred record owned and maintained by the patient; timely follow-up with primary or specialty care; list of "red flags" indicative of worsening condition and how to respond to them	Randomized controlled trial with 750 medical patients randomized into intervention and control groups. Primary outcome: rate of non-elective rehospitalization at 30, 90, 180 days post discharge after index hospitalization	Intervention patients had significantly lower re-admission and rates at all intervals and lower hospital costs.	Shaping knowledge Antecedents (adding objects to the environment) Feedback and monitoring Natural consequences Goals and planning
41	US	Care Coordination	Program for medical patients being discharged. 4 pillars: assistance with medication self-management; patient-centred record owned and maintained by the patient; timely follow-up with primary or specialty care; list of "red flags" indicative of worsening condition and how to respond to them	Quasi-experimental design with 158 medical patients receiving intervention and comparison with administrative data for 1,235 controls	Significant decrease in re-hospitalizations for intervention group at 30, 90 and 180 days. Participants receiving the intervention reported high levels of confidence in obtaining essential information for managing their condition, communicating with the health care team	Shaping knowledge Antecedents (adding objects to the environment) Natural consequences Goals and planning

					and understanding their medication regimen.	
42	US	PFCC: Care Planning	Integrate self-assessment and self-reporting using e-health platform (iPad) to deliver personalized care plan while hospitalized. iPad loaded with software designed to support recovery and discharge planning after cardiac surgery.	Survey of 149 patients who completed 1,418 assessments (97.6% completion)	e-Health platform, combined with mobile computing, can deliver customized care with which patients can interact. PROs have predictive value for resource use and outcomes.	Feedback and monitoring (Self-monitoring of behavior) Antecedents (Adding objects to the environment)
43	US	Care Coordination	Developed a prototype low-literacy medication education tool, customizable for each patient, using icons and photos of pills	Interviews of 166 participants two weeks and 85 participants 4 weeks after discharge	Participants who received the intervention self-reported their medication adherence more accurately and demonstrated improved knowledge about the purposes of their medications, but there was no effect on self-reported medication adherence	Antecedents (Adding objects to the environment) Regulation (Conserving mental resources)
44	US	PFCC: Communication	Provided access to iPad to input goals, preferences, concerns; view team goals, problems and schedule of events; access educational content; send messages to care team	Evaluation of usage in 239 patients and caregivers. 18/32 patients completed system usability	Most frequent use was to send messages related to health concerns, needs, preferences or questions. Use of educational content highest for medications	Goals and planning Antecedents (Restructure social environment;

				and satisfaction survey.	and test results and lowest for problems	Adding objects to the environment)
45	UK	PFCC: Care planning	Goal setting meetings with patient, relative as needed and multidisciplinary team	Case-controlled retrospective study of 105 patients comparing the number of goals set between patients admitted before and after goal-setting process introduced.	Significant increase in number of goals set per patient. Proportion of goals achieved similar to pre-intervention	Goals and planning Antecedents (Restructure social environment)
46	UK	Patient Safety	PINK is a 4 minute animated video aimed at helping patients prevent errors by encouraging to : Participate; be Informed; Notice and be alert; and Know what they can do to facilitate their recovery	Within-subjects pre- and post-screening of safety video using questionnaires with 201 patients and 95 health professionals	Post-video patients were more positive about asking doctors and nurses if they had washed their hand and notifying them about issues to do with personal hygiene. No effects on patients notifying staff about not receiving medications or in pain or unwell. Providers were more willing to support patient involvement post-video.	Shaping Knowledge Antecedents (adding objects to the environment)

47	UK	Patient Safety	Safety video (Study 1) and leaflet (Study 2) encouraging participation in safety-related behaviors	Exploratory, pre-post, within-subjects mixed methods design studies with 80 participants in each study	Increased comfort reported in engaging in some, but not all, safety-related behaviors. Patients questioned whether intervention would help reduce medical error.	Shaping knowledge Antecedents (adding objects to the environment)
48	AU	PFCC: Communication	Goal-setting interviews in rehabilitation	Exploratory, mixed methods study of 22 triads (patients, family and provider)	Provider views dominated the goal setting process. Strategies to promote goal-setting through supporting the unknown experience of injury and hospitalization: build trust; be responsive; open and honest approach.	Goals and planning
49	US	PFCC: Care planning	Family and team discussion of palliative medical condition, patient and family understanding of treatment option and disease burden, directions of medical care	Survey of 140 family caregivers post-intervention; observational data on emotional expression collected during meetings	Frequent expressions of distress from patients and families. Questions were infrequent, Patient presence significantly associated with increased discussion of goals of care, prognosis and expected symptoms at death, but decreased	Goals and planning Antecedents (Restructure the social environment)

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					discussion of medical information.	
50	The Netherlands	PFCC: Communication	Passport describes, records and evaluates medical screening results to achieve treatment goals.	Qualitative (focus groups with 29 patients and 21 providers)	Purpose of passport unclear to patients. Reviews were mixed on ease of use, responsibility for completion and usefulness as an adjunct to management of diabetes. Patients expected little co-operation from internists. Barriers to fitting passport into organization of diabetes care.	Feedback and monitoring Antecedents (Adding objects to the environment)
51	UK	PFCC: Care planning	Care planning meetings including older adults	Focus groups of 20 care providers	Benefits of collaborative decision-making confirmed, although concerns about the quality of participatory practices, limited attention to group process and exclusion of those with cognitive impairment were identified	Goals and Planning
52	US	PFCC: Communication	Families invited to be present during attempted resuscitation	Survey of 70 family members	94% would participate again; 76% said grieving was facilitated by witnessing the resuscitation; 64% felt	Antecedents (Restructuring the social environment)

					their presence was beneficial to the patient	
53	US	Patient Safety	Personalized bedside screensaver of a patient safety plan that captured data from the electronic health record, including icons common to geriatric syndromes.	Phase 1: 21 end users including 6 patients participated in interviews. Phase 2: 22 end users including 6 patients participated in interviews	The Meaningful Use Program in the US requires providers to engage their patients in their health care through technology. Patients and families did not question the data on the screen saver, although some providers questioned its accuracy. Generally viewed positively, although additional work remains to be done on functionality.	Antecedents (adding objects to the environment)
54	UK	Patient Safety	“Clean Your Hands” Campaign. Study measured the effect of MRSA awareness or knowledge on patients’ willingness and comfort level in asking staff about hand-washing.	Survey of 185 patients with a response rate of 58.9% (n=109)	Access and availability of patient information about the campaign was absent. Patients were knowledgeable and aware of risks of infect while hospitalized.	Shaping knowledge Antecedents (adding objects to the environment)
55	US	PFCC: Care Environment Programs	Structured patient-centred care and engagement training program and web-based technology including ICU safety checklist, tools to develop a shared care plan and messaging platform	Prospective pre-post study of 1,030 pre and 1,075 post patient admissions	Aggregate rate of adverse events dropped by 29% during the intervention period. Patient/family satisfaction improved markedly from 71.78 to	Antecedents (Restructuring the social environment; Adding objects to the environment)

			were used by patients and care partners to view health information, participate in their care plan and communicate with care providers.		93.3 for patients. No changes were found in care plan concordance or resource utilization.	
56	US	PFCC: Communication	Electronic Bedside Communication Centre (eBCC) prototype to activate patients and bridge communication gap with professionals	Individual interviews and focus groups	The eBCC was useful and easy to use, but there were issues trying to message the team and the ability to participate in developing the plan of care. Toolkit may be confusing for older patients or those uncomfortable with technology.	Antecedents (adding objects to the environment)
57	Norway	Care Coordination	Meeting Point program consists of three seminars and four follow-up meetings with health professionals from diverse settings focused on enhancing patient participation in transitional care.	Written feedback from 85 health professionals, minutes from the plenary sessions, log reports of group facilitators and participants' written notes. Follow-up meetings were recorded and transcribed.	Program was useful in increasing providers' awareness of and competencies related to the patient's perspective in transitional care.	Shaping knowledge Identity (Framing/re-framing)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15	58	Denmark	PFCC: Care Environment Programs	Psychiatric patients with a contract can initiate a brief admission without a health professional gatekeeper	190 patients evaluated 492 admissions. The majority sought early help for mental health conditions, but also for social and everyday problems.	Primary reason was to be at peace and prevent symptom increase. Two-thirds of the patients were satisfied, although those who hoped to improved medication or wished to obtain more care were less satisfied.	Feedback and monitoring (Self-monitoring of behavior) Antecedents (Restructure the social environment)
16 17 18 19 20 21 22 23 24 25 26 27 28	59	UK	PFCC: Care Environment Programs	Developed charters, information packages, health professional visibility strategies for cardiac patients. Flexible family visiting, facilitated and supported carer involvement in care provision and improved partnership between carers and team	Pre-post intervention surveys of 43 patient and 63 carers pre- and 56 patients and 68 families post	Improved carer recognition and increase in degree they felt listened to, included, involved and supported. Noted reduction of complaints to 0 over intervention period, supporting the finding of better communication.	Antecedents (Restructure the social environment; adding objects to the environment) Social support (Practical and emotional)
29 30 31 32 33 34 35	60	US	Patient safety	Patient-held, patient-friendly medication schedule with printed reported reviewed with patients	Surveys of 100 patients	Providing patients with schedule made them partners in health care decision and provided them with knowledge about medications.	Antecedents (adding objects to the environment)
36 37 38 39 40 41 42 43 44 45 46 47	61	UK	PFCC: Communication	Trauma patients view radiographs on tablets	Pre- and post-intervention study of 2 cohorts of 50	Post-intervention patients reported significant increase in scores for perceived involvement in	Antecedent (Adding objects to the environment; restructuring

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				consecutive patients	decisions made about their care and being given the right information	the social environment)
62	AU	PFCC: Communication	Care bundle for medical and surgical patients: Checklist/brochure, video and posters developed by health professionals, researchers and patients	Interviews of 11 patients who had used the care bundle	Care bundle generally well-received by patients, although they did not make use of the checklist	Shaping knowledge Antecedents (adding objects to the environment)
63	AU	PFCC: Communication	Point of service feedback using paper-based or electronic questionnaires	Cross-sectional survey of 247 patients and 221 staff	Patients preferred to give feedback during stay rather than after discharge, give feedback verbally rather than by questionnaire. Some patients feared reprisal if they gave negative feedback. Staff agreed patients should be invited to give feedback during stay. Primary reason to provide feedback was to improve services. Feedback varies with data collector.	Antecedents (adding objects to the physical environment)
64	Canada	PFCC: Care Environment Programs	Enhanced Recovery after Surgery (ERAS) is a 22 element program designed to reduce morbidity and length of hospital stay.	20 patients who had undergone colorectal surgery in past 12 months	Overarching concept was that patients wanted to take responsibility for own health from diagnosis	Shaping knowledge Natural consequences

			Many of the elements are dependent upon patient adherence. Patient engagement framework developed. Goal was to build patient capacity within the ERAS program.	participated in patient-led focus groups and interviews. Seven patients participated in a co-design focus group to set and prioritize the research.	to recovery. Concluded no single model for patient engagement can be developed due to different cultures and contexts.	
65	US	PFCC: Communication	“Condition H” allows patients and families to initiate call to Rapid Response Team themselves.	Interviews with 21 patients and families involved with 21 Condition H events	Patients and families unanimously favorable. Most calls were related to communication issues or disagreement with treatment.	Feedback and monitoring Antecedents (Restructuring social environment; adding objects to the environment)
66	US	PFCC: Communication	Tablets used to provide health education modules (safety and discharge) and provide access to personal health records	Survey of 30 patients	Majority reported high overall satisfaction with the device, required <30 minutes of orientation. 83% completed safety module and 70% accessed their hospital record.	Antecedents (Adding objects to the environment) Shaping knowledge Feedback and monitoring
67	US	PFCC: Care Environment Programs	Wellness approach and focus on empowering medical patients/families during their stay. Live-in	Costs and health care utilizations data over 10 years	Reduced lengths of stay. 38.4% savings per hospitalization. Requires strict criteria and appropriate space.	Social support Antecedents (Restructuring the social environment)

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			family or friend care partner actively involved in care.			
68	Germany	PFCC: Communication	Five one hour training sessions, including practice and feedback, for psychiatric patients on shared decision-making, including motivational and behavioral aspects	Randomized controlled trial of 61 inpatients (32 in intervention group). Control group received cognitive training.	Shared decision making training resulted in high participation preferences and increased desire to have more responsibility in treatment. Patients receiving intervention became more skeptical and were perceived as more "difficult" by psychiatrists.	Shaping knowledge Repetition and Substitution Feedback and monitoring
69	AU	Patient Safety	Patients and staff falls prevention education program ("Safe Recovery Program") comprised of DVD, workbook and 1-3 individualized sessions with physiotherapists that had been delivered to 750 patients	Qualitative exploratory study (N=10) with 9 participating in focus groups and 1 in telephone interviews, field notes	Individualized falls prevention education provides patients with capability and motivation to develop and undertake behavioral strategies to reduce falls. Educators could participate in engagement and reconciliation with staff to improve communication and outcomes.	
70	Japan	Effective Treatment	Daily voluntary training in addition to standard rehabilitation.	Clinical trial with 29 participants (21 intervention)	Voluntary training with family participation reduced length of stay and improved the rate of home discharge	Shaping knowledge Feedback and monitoring

						Repetition and Substitution
71	US	PFCC: Communication	Evidence-based communication intervention bundles at 24, 72, 96 hours after admission to ICU. Included introduction to staff, resource folder, video, pain education, care model, resources.	Pre- and post-test design using process improvement methods. 41 pre-intervention surveys and 48 post-intervention surveys.	Family satisfaction scores for participation in decision-making and ratings of how well the team worked together showed statistically significant improvement following the intervention.	Shaping knowledge Antecedent (Restructuring social environment) Antecedents (adding objects to the environment)
72	Sweden	PFCC: Communication	Detailed written information regarding possible complications of surgery	Surveys of 182 (intervention) and 156 (control) patients undergoing surgery.	Majority of both intervention and control groups wanted more information about both common and rare complications. Intervention group significantly more satisfied with all aspects of information compared to control group both pre- and post-op.	Shaping knowledge Antecedents (adding objects to the environment)
73	US	PFCC: Care Planning	Families of ICU patients invited to participate in daily interdisciplinary rounds where team discussed plan of care.	Survey of 227 family members before and after implementation of family rounds.	Overall satisfaction scores did not differ between families who attended rounds and those who did not. Certain elements of	Antecedents (Restructuring the social environment)

					satisfaction improved, but overall satisfaction. Some families can benefit, but some feel rushed to make decisions.	
74	Sweden	PFCC: Communication	Patient-written "Tell-us" card (indicate what was most important for the patient that day) on patient perceptions of quality of care.	Quasi-experimental design using consecutive sample of 310 patients	Use of the Tell-us card resulted in significant improvements in 5 out of 17 items related to participation in decisions about medical and nursing care.	Feedback and monitoring Antecedents (Restructuring the social environment) Antecedents (adding objects to the environment)
75	Sweden	PFCC: Communication	"Tell-us" cards were used by patients to write goals for the day and indicated what mattered to them.	Interviews with 198 patients and 5 nurse managers	No improvements noted in patient participation, although culture shift noted in which staff grew to accept patients' involvement in their own care.	Feedback and monitoring Antecedents (Restructuring the social environment) Antecedents (adding objects to the environment)
76	Canada	PFCC: Bedside nursing handover	Shift hand-over conducted at medical-surgical and Ob/Gyn patients' bedsides.	Interviews with 45 patients.	Themes: creating a space for personal connection; enabled	Antecedents (Restructuring

					patients to be kept up to date; varying preferences (some patients did not see the need for bedside hand-over).	the social environment)
77	Canada	Patient Safety	Awareness campaign with 5 key safety tips for patients.	Survey of 108 hospital stakeholders (e.g. directors) and focus groups with the public.	Stakeholders were enthusiastic, although patient awareness of the campaign was low.	Shaping knowledge Antecedents (adding objects to the environment)
78	Finland	PFCC: Care Environment Programs	Activation programs for informal caregivers (booklets, invitation to participate in care); policy change (participate in an annual conference with other relatives and visitors, staff, researchers)	Interrupted time-series design with control groups of 369 caregivers conducted in 3 settings (university hospital; geriatric unit of a health centre and a nursing home)	Total participation of caregivers increased in long-term care, but not in the hospital.	Shaping knowledge Social support Antecedents (adding objects to the environment)
79	AU	PFCC: Care Environment Programs	New practice standards designed to encourage participation.	Survey of 86 community patients. Pre-post chart audits of 30 inpatient and 25 community	Modest and consistent improvements in documented carer participation were found.	Antecedents (Restructure the social environment; adding objects to the environment)

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				patients (pre-), and 30 inpatients and 29 community patients (post-).		Goals and Planning
80	Germany	Patient Safety	“Patients and Families as Teachers in Patient Safety” brought interprofessional clinicians together with patients and families in 4 hour collaborative learning experience, including simulation, focused on developed patient-centred medical error disclosure communication skills.	Mixed methods with pre-post survey with qualitative and quantitative items. 55 clinicians and 18 patients and family members completed the program.	Bringing clinicians, patients and families together to discuss medical error was acceptable and feasible. Patients and families wanted to know “how the provider thinks” and more about medical error. They were interested in strategies for partnering with clinicians for safety. Patients valued experiencing clinicians’ send of accountability following medical mistakes; gained insight into the emotional impact of making an error for clinicians;	Antecedents (restructure social environment) Shaping knowledge Repetition and substitution Comparison of behavior (demonstration)
81	US	PFCC: Communication	“Go Wish” card game designed to allow seriously ill patients to consider the importance of common issues at the end of life so	Observational study of 67 patients using survey and patient rankings of goals and	25% of patients were able to complete the game. Highest value was “to be free of pain”. The card game is	Goals and Planning Antecedents (Adding objects to the environment)

			patients are prepared for discussions.	values after the game	feasible for use in inpatient settings.	
82	UK	Patient Safety	Patient Reporting and Action for a Safe Environment (PRASE) intervention consisted of: a) Patient Measure of Safety (PMOS) Questionnaire and b) a form for patients to report both safety concerns and positive experiences (patient incident reporting tool). Feedback considered in team meetings.	Clusters included 33 hospital wards within 5 hospital.	No significant effects on ward-level harm-free care and patient-level feedback on safety. Intervention uptake and retention was 100%.	Antecedents (Adding objects to the environment) Feedback and monitoring
83	UK	Effective treatment	“GetREAL” program for psychiatric patients in rehabilitation programs with predisposing, enabling and reinforcing stages	Qualitative study of 59 patients using focus groups of staff within a clustered RCT.	Intervention accepted by staff, but skills and changes to processes and structures were not sustained at the conclusion of the program. External factors such as resources limitation, lack of senior staff support, competing priorities and intensive training contributed to findings.	Antecedents (Restructuring the social environment; adding objects to the environment) Goals and planning (Commitment) Repetition and substitution
84	US	Patient Safety	Patients presented with a “Partners in Your Care” script asking them to remind health care workers to wash their hands; compliance reassessed using a modified	Interviews and direct observations of 193 patients.	Only 3% reminded at least one worker to wash their hands and 8% did not comment on hand hygiene after observing workers fail	Antecedents (adding objects to the environment) Feedback and monitoring

			script where patients were asked to thank workers for washing and/or display a sign saying "Thanks for Washing"		to wash hands. Patients are unlikely to remind workers to wash their hands.	Association (prompts and cues)
85	US	PFCC: Communication	Alert ICU patients or family members of patients who met criteria for physiological or anatomic activation of the trauma team with subsequent resuscitation were offered the option of families being present during resuscitation.	Analysis of self-administered survey of a convenience sample of family members of 140 trauma patients (70 not present during resuscitation).	Being present during resuscitation associated with reduced anxiety, reduced stress and fostered well-being,	Shaping knowledge Antecedents (restructuring the social environment)
86	Sweden	PFCC: Communication	Geriatric patients invited to team meeting which replaced rounds.	Phenomenological study with 9 nurses	Patient participation can be supported by a safe relationship in which the patient can make his or her voice heard. Participated is challenged by patients' vulnerability and by the subordinated role assigned to the patient.	Antecedents (Restructuring the social environment)
87	Canada	PFCC: Care Environment Programs	Established peer support program for psychiatric patients, strengthened patient advisory committee and creating a patient-led research team	Prospective, longitudinal approach (T1 and T2) with 25 patients. 28 providers were surveyed at T1 and T2.	Intervention had minimal impacts on internalized stigma, personal recovery, personal empowerment, service engagement, therapeutic milieu and	Social Support Antecedents (Restructuring the social environment)

					recovery orientation of services.	
88	UK	Patient Safety	Patient Reporting and Action for a Safe Environment (PRASE) consisting of Patients Measure of Safety (PMOS) and Patient Incident Reporting Tool (PIRT) enables patients to reported detailed safety concerns and/or positive experiences. Anonymous feedback collecting using these tool present to ward staff in the form of a feedback report, followed by iterative planning cycle.	Focus groups with hospital volunteers (n=15), voluntary and patient experience staff (n=3). Semi-structured interviews with ward staff (n=5).	All stakeholders were positive about the PRASE intervention as a way to support service improvement and the benefits of including volunteers. Volunteers felt adequate training and support would be essential for retention. Staff raised concerns about infrastructure and sustainability.	Antecedents (adding objects to the environment) Feedback and monitoring
89	Spain	Effective Treatment	Individualized graduated exercise program with monitoring. Education of patients, caregivers and staff to promote mobility and functional independence	Prospective clinical trial of 17 intervention and 12 control participants.	An early supervised exercise program can reduce decline and can be maintained or improved when families are involved.	Feedback and monitoring Shaping knowledge Antecedents (adding objects to the environment)
90	UK	Patient Safety	“Partner in Your Care” program where medical-	Controlled prospective	62% of patients felt comfortable asking	Feedback and monitoring

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			surgical patients asked all healthcare workers who were going to have contact with them "Did you wash your hands?"	intervention study of 39 patients. Compliance measured through soap/alcohol usage and handwashings per bed.	about handwashing. All patients asked nurses, but only 35% asked physicians.	Shaping knowledge
91	AU	PFCC: Bedside nursing handover	Nursing bedside handover	Descriptive case study of 10 patients	Patients appreciated being acknowledge as partners in care. Bedside handover was the opportunity to correct inaccuracies in information being communicated. Some patients preferred passive engagement.	Antecedents (Restructuring the social environment)
92	Norway	PFCC: Care Environment Programs	Government-legislated patient participation in care	Interviews with 15 older adults admitted to geriatric wards.	The values of older adults of community and solidarity may differ from the focus on individualism that underpins legislation. Patients often authorized family members to act and participate on their behalf due to their own declining capabilities and the hospitals' busy schedules.	Goals and Planning Antecedents (Restructuring the social environment)

93	UK	Patient Safety	Call 4 Concern is a scheme where patients and relatives can call critical care teams if they are concerned about a patient's condition.	Surveys completed by 11 patients transferring out of ICU to general wards over a six month period, 11 relatives and 4 others and 57 ICU staff members.	Patients and families felt reassured. Staff felt the system could prevent deterioration, but were concerned about inappropriate calls, increased workload and de-skilling of ward staff.	Antecedent (restructure social environment) Shaping knowledge
94	US	PFCC: Communication	Given tablets with a mobile patient portal application including pictures, names and role descriptions of team members, scheduled tests, procedures and a list of active medications.	100 intervention and 102 control-unit participants.	Significantly higher proportions of intervention named more than one physician and physician role. No difference in knowledge of nurses' names, planned tests, procedures or medications were noted between the units. No change in activation score.	Shaping knowledge Antecedents (Adding objects to the environment)
95	Finland	PFCC: Care Environment Programs	Mental health patients who are well-known to providers can refer themselves to short inpatient stays.	42 qualitative, semi-structured interviews with 28 patients with serious mental illness	Having the option to self-refer enhanced patients confidence in the services they use and in their own ability to cope with everyday life.	Antecedent (restructure the social environment) Feedback and monitoring (self-monitoring)

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96	US Canada	PFCC: Care Planning	Morning interprofessional rounds used in critical care to improve team-based care, patient outcomes and involve patients and families.	Ethnographic study with 576 hours of observation, 47 shadowing experiences and 40 clinician interviews.	Rounds conducted at threshold of patient room, rather than inside of them. Involving patients was seen to “inevitably and uselessly prolong rounds”. Patient interactions were rare. Physicians felt time constraints necessitated more time spent teaching interns and less on interacting with or including patients in their own care.	Antecedents (Restructure the social environment)
97	US	PFCC: Communication	Detailed, personalized information about injuries, acute care treatment and rehabilitation progress was provided.	2x2 factorial design with 28 patients.	Intervention patients exerted greater effort in physical therapy, made greater improvement in functional independence and were more satisfied with rehab treatment.	Shaping knowledge Antecedents (Restructure the social environment; adding objects to the environment)
98	UK	Patient Safety	A 4 minute animated video entitled “PINK” aimed at helping patients prevent errors by encouraging them to : Participate; Be informed; Notice and Be alert; and Know what they	Qualitative semi-structured interviews with 36 patients	Overall favorably received. Benefits included raising awareness and facilitating patients to be involved in care. Less certainty about its	Antecedents (adding objects to the environment) Shaping Knowledge

			can do to facilitate their recovery		ability to enhance safety. Different groups may require more tailored content in videos.	Comparison of behavior (demonstration)
99	Canada	PFCC: Care Environment Programs	“Patients as Partners” concept in programming considers medical patient full-fledged members of health care team. Uses competencies and practices for both patient and providers.	Grounded theory study with 16 semi-structured patient interviews of those who participated as “patient trainers’ co-leading inter-professional collaboration courses.	Patients described themselves as: a) continuously learning about their health; b) assessing the quality of health care received and c) adapting and compensating for optimal or non-optimal care, taking more control over decisions with their own care.	Antecedents (Restructure the social environment)
100	Norway	PFCC: Care Environment Programs	Development plan in one mental health hospital (intervention) included: establishing a patient education center, a user office, purchasing user expertise, appointing contact professionals for next of kin, improve center’s information and culture	Non-randomized controlled study using a survey of 438 professionals to compare outcomes between intervention and 2 control groups in different hospitals.	No statistically significant differences in professionals’ knowledge, practice or attitudes.	Antecedents (restructure the social and physical environments; adding objects to the environment)

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14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	102	Israel	PFCC: Care Planning	Ward (medical) rounds were conducted with and then without the presence of family members.	Prospective 2-phase survey study of 26 (phase 1) and 23 (phase 2) nurses and physicians, 26 and 35 patients and 32 and 40 family members	Hospitalized patients wanted family members to participate in rounds. Staff were initially reluctant, but gradually more accepting. Patients felt they had a better understanding of their medical conditions. Families felt they had more opportunity to participate in decision-making. Adjustment to the structure of rounds is necessary.	Antecedents (Restructure the social environment)
32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47	103	US	PFCC: Communication	Computer-processed information about geriatric patient preferences for self-care capability were placed in the patients' charts for staff to use in care planning.	Three group quasi-experimental design with one experimental and 2 control groups (n=151)	Information about patient preferences changes nurses' care priorities to be more consistent with patient preferences and improved patients' preference	Shaping Knowledge Goals and Planning Antecedents (adding objects to the environment)

					achievement and physical functioning	Feedback and monitoring
104	Norway	PFCC: Care Environment Programs	CHOICE is a palm-based decision support system for preference-based acute care planning that elicits patient preferences for functional performance at the bedside and to select care priorities consistent with patient preferences	Three group quasi-experimental design with one experimental and 2 control groups	Nurses' use of CHOICE changed nursing care to be more consistent with patients preferences and improved patients' preference achievement	Goals and Planning Antecedents (Restructuring the social environment; adding objects to the environment)
105	US	PFCC: Bedside nursing handover	End-of-shift report at patient bedside. Training video, hand-outs, scripts for handovers provided to nurses.	Pre- and post-survey of 232 (pre) and 178 (post) patients, 70 (pre) and 72 (post) family members and nurses. Data on Patients falls during shift change, medication errors and nurse overtime was also collected.	Statistically significant difference in patients feeling included in shift report and believing that important information was communicated between shifts. Both falls and medication errors during shift change decreased. Improved nurse perceptions of nursing accountability and patient involvement in care.	Shaping knowledge Antecedents (Restructure social environment; adding objects to the environment)
106	Singapore	Effective treatment	Patient education intervention to enhance self-efficacy of hospitalized medical patients to recognize and report symptoms of acute deteriorating conditions	Cluster RCT of 34 (intervention) and 33 (control) patients.	Level of self-efficacy in experimental group was significantly higher than control group.	Shaping knowledge Antecedents (Restructure the social environment; adding objects

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						to the environment)
107	US	PFCC: Communication	Whiteboards at medical patients' bedside can be a communication tool between hospital providers and a mechanism to engage patients in care	Survey of 104 nurses, 118 house staff and 31 hospitalists	While providers valued family contact information on the whiteboard, nurses valued the importance of goals and discharge dates more than physicians. Few providers felt patients or families should be responsible for the information on the board or be involved in creating goals.	Antecedents (adding objects to the environment) Goals and Planning
108	US	PFCC: Care Environment Programs	Engagement of nurses, physicians, administrators and security in creating open visitation policy in acute care and rehabilitation hospital.	14,444 after-hours visit recorded	No increase in number of complaints from patients or visitors. Security event numbers remained the same. Unit staff received few phones calls for patient updates. Patient satisfaction scores showed positive trends but no significant change.	Antecedents (Restructure the social environment)
109	US	Effective treatment	Telephone-administered health behavior change counseling (brief motivational interviewing) of surgical patients.	Prospective clinical trial of 59 (control) and 63	Patient activation predicted engagement. The influence of counseling on rehab engagement was	Social support Regulation Antecedents: Restructuring

				(intervention) patients	mediated by patient activation.	the social environment
110	US	PFCC: Communication	Psychiatric patients given daily access to medical records with a nurse available to assist.	Survey of 88 patients and 20 staff	Patients reported feeling better informed and more involved in their treatment. Staff said they became more thoughtful about their notes.	Antecedents (Restructure the social environment)
111	Sweden	PFCC: Care Planning	Medical patient participation in ward rounds	Descriptive study of 14 inpatients who participated in interviews.	Aspects of ward rounds could be improved to promote information exchange. Information from nurses was easier to understand than information from physicians. Rounds must have an open atmosphere. Patients must be treated with empathy by staff and their right to participate acknowledged.	Antecedents (Restructure the social environment) Goals and Planning
112	Finland	PFCC: Care Planning	Afternoon reporting at surgical patients' bedsides	Survey of 118 nurses and 74 patients with observation of 76 bedside reporting sessions	Three minutes were used to give each patients' report. Patients felt this time was too short. One third of patients felt uncomfortable when other patients were present. Differences between nurse and	Antecedents (Restructure the social environment) Feedback and monitoring

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					patient perceptions in terms of purpose of rounds and whether patients were to participate.	
113	Austria	PFCC: Care Environment Programs	Training program aimed at providers for empowering cardiac patients to be more effective co-producers of recuperation from surgery. 2 hour didactic session for all staff and additional 3 hour training for physicians which included role play, supervision of 3 ward rounds, admission and discharge communications.	Case study of 100 (control) and 99 (intervention)	Length of stay reduced by 1 day, incidence of post-surgical tachyarrhythmias reduced by 15%, transfer speed improved and patient rating of provider communication were improved.	Shaping knowledge Antecedents (Restructure the social environment)
114	UK	Patient Safety	“Medicines with Respect” program provided a foundation for the administration of medication and medication management strategies with client involvement. Skills training for nurses, assessment and set of clinical guidelines.	67 patient questionnaires and unspecified number of staff evaluations.	More patients were given written information; being given their medication individually instead of in a queue; improved patient compliance with medications; more carers were given sufficient information. No difference in explanations for rational for medication or patient understanding.	Antecedents (restructure social environment) Antecedents (adding objects to the environment)

115	The Netherlands	PFCC: Care Environment Programs	SAFE or SORRY program consisted of essential recommendations from guidelines on the prevention of three adverse events (pressure ulcer, falls and urinary tract infections) prevalent in older adults. Education, patient involvement and feedback occurred through a computerized registration system.	Cluster RCT of 10 wards from 4 hospital with 2201 patients and ten wards from six nursing homes with 392 patients.	Hospitalized patients receiving the intervention suffered 43% fewer adverse events than control groups. Rate ratios for the development of an adverse events were statistically significant (OR=0.57, CI 0.34-0.95) for hospital patients receiving the intervention.	Shaping knowledge Antecedents (adding objects to the environment) Feedback and monitoring
116	Sweden	PFCC: Care Planning	The Canadian Occupational Measure (COPM) is a patient-centred instrument that provides a structure for formulating treatment goals identified by the client in cooperation with the occupational therapist through an interview.	Experimental design with 155 patients in the intervention group and 55 in the control group. Structured interview with 88 patients in the intervention and 30 in the control group.	Compared to the control group, more patients in the experimental group perceived that treatment goals were identified, felt they were active participants in the goal formulation process and perceived themselves better able to manage after completed rehabilitation.	Goals and Planning Antecedents (Restructure the social environment) Antecedents (adding objects to the environment)
117	UK	PFCC: Care Planning	Goal-setting meetings for rehabilitation patients.	Qualitative study of 4 cohorts of 10 patients, carers or staff with different	All groups found goal setting beneficial, increasing motivation and providing reassurance for patients and carer.	Goals and Planning Antecedents (Restructure the social environment)

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				experiences in goal-setting	Carers found goal setting alleviated anxieties and assisted active problem-solving coping strategies. Staff believed goal setting made their practice more focused and collaborative,	Social support
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For peer review only

BMJ Open

Building patient capacity to participate in care during hospitalization: A scoping review

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4 **A Scoping Review**
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Abstract

Objectives: To map the existing literature and describe interventions aimed at building the capacity of patients to participate in care during hospitalization by: a) describing and categorizing the aspects of care targeted by these interventions; and, b) identifying the Behavior Change Techniques used in these interventions. A patient representative participated in all aspects of this project.

Design: Scoping review.

Data sources: MEDLINE, Embase and CINAHL (Inception -2017).

Study Selection: Studies reporting primary research studies on building the capacity of hospitalized adult patients to participate in care which described or included one or more structured or systematic interventions and described the outcomes for at least the key stakeholder group were included.

Data Extraction: Title and abstract screening and full text screening were conducted by pairs of trained reviewers. One reviewer extracted data, which was verified by a second reviewer. Interventions were classified according to seven aspects of care relevant to hospital settings. Behavior change techniques identified in the articles were assigned through consensus of three reviewers.

Results: Database searches yielded a total 9,899 articles, resulting in 87 articles that met the inclusion criteria. Interventions directed at building patient capacity to participate in care while hospitalized were categorized as those related to improving: patient safety (20.9%); care coordination (5.7%); effective treatment (5.7%); and/or patient-centred care using: bedside nursing hand-overs (5.7%); communication (29.1%); care planning (14%); or the care environment (19.8%). The majority of studies reported one or more positive outcomes from the defined intervention. Adding new elements (objects) to the environment and restructuring the social and/or physical environment were the most frequently identified Behavior Change Techniques.

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3 **Conclusions:** The majority of studies to build capacity for participation in care report one or more
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5 positive outcomes, although a more comprehensive analysis is warranted.
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9 **Strengths and Limitations of the Study**
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- 13 • Identification of behavior change techniques used in included studies highlights the importance
14 of behavior change as foundational in interventions designed to build hospitalized patient
15 capacity to participate in care.
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 - 18 • Because building capacity of hospitalized patients to participate in care can take many forms,
19 the aims, interventions and study designs included in this review were heterogeneous and
20 largely descriptive.
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 - 23 • Exclusion of grey literature, articles published in languages other than English and articles
24 published after August, 2017 are limitations of the study.
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 - 27 • Formal measurement of agreement levels between coders was not performed during the coding
28 training sessions.
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 - 31 • Patient focus groups were not included in the scoping review process. Additional patient
32 representatives on this project may have contributed to broader patient perspective.
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44 **Keywords:** Patient participation; patient-centred care: behavior change techniques; hospitals; quality
45 improvement
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47 Word Count: 3886
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1. Introduction

Improving the safety, quality and patient-centredness of care delivered in hospitals is well-recognized as a global priority^{1,2}, with increasing recognition of the potential of patient engagement to contribute to the improvement agenda.^{3,4} Patient engagement is defined by the WHO as “the process of building the capacity of patients, families, carers and health care providers, in order to enhance safety, quality and patient-centredness of health care delivery”.⁵

Effective engagement of patients in care provided during hospitalization has been associated with better self-management,⁶⁻⁷ fewer adverse events,⁸ and diagnostic tests,⁹ decreased use of health services,¹⁰ and shorter lengths of stay.¹¹ Patients and families who are engaged in care have opportunities to provide information essential to appropriate care planning,¹² to recognize errors in care delivery,¹³ and to adhere to treatment plans.¹⁴ Additional benefits of effective patient and family engagement include: enhancing system responsiveness to evolving user needs¹⁵; promoting decision-making transparency and improving quality^{16,17}; and reducing cost and waste.¹⁵

The quality challenges common to health care systems include the need to improve patient safety, patient-centred care, coordination of care, effective prevention and treatment, healthy living and care affordability.¹⁸ Within hospital settings, high acuity and rapid patient turn-over represent barriers to effective patient participation in care to an extent not found in other health care settings. Wide variability in the implementation of practices designed to promote patient and family engagement was identified in a survey of U.S. hospitals.¹⁷ These practices were classified into the following categories: a) organizational (e.g., formal policy for disclosing medical error); b) bedside (e.g., participation in shift change report); and, c) access to information and shared decision-making (e.g., online access to personal health information).

Better understanding of the characteristics of interventions aimed at building the capacity of hospitalized patients to participate in care is important for building the evidence base in this area and

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3 strengthening the theoretical underpinnings of future interventions at the design phase. Successful
4 implementation of these types of interventions may be facilitated by the incorporation of systematic
5 methods such as behavior change techniques (BCTs) for characterizing interventions and linking these to
6 an analysis of the targeted behavior.^{19, 20} BCTs are defined as “observable, replicable and irreducible
7 component[s] of an intervention designed to alter or redirect causal processes that regulate behavior”.

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¹⁹ The BCT Taxonomy can offer a reliable and systematic framework for the identification of the “active, effective” components within specific interventions¹⁹, provided sufficient detail is provided about the intervention.²¹

Given the dynamic state of evidence describing interventions to promote patient participation, a scoping review was the most appropriate method to produce a narrative integration of relevant evidence addressing our broadly defined question.²¹ Although efforts to intentionally build capacity to participate in care have become a priority in many hospitals, much remains to be learned about how to best accomplish this goal. *In order to advance the evidence base in this area, this scoping review aimed to map the existing literature and describe interventions aimed at building the capacity of patients to participate in care during hospitalization.* Our specific research questions were to: a) describe and categorize the aspects of care targeted by these interventions; and b) identify the behavior change techniques used in the interventions to build patient participation in care.

2. Methods

2.1 Design

As one form of knowledge synthesis, scoping reviews provide narrative integration of relevant evidence by mapping key concepts, types of evidence and gaps in research to address a broad question investigating a particular field.²² To date, there have been no syntheses of the interventions designed to build capacity of hospitalized patients to participate in care. The original protocol for this review was published in 2018.²³

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3 This systematic scoping review has allowed us to determine the extent, range and nature of
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5 research activity related to initiatives designed to build the capacity of hospitalized patients to
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7 participate in care. Guided by the methodology proposed by Arksey and O'Malley²² and its subsequent
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9 revisions,^{24,25} this review included the following steps: a) identifying the research question; b)
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11 identifying relevant studies; c) describing study selection criteria; d) charting the data; and e) collating,
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13 summarizing and reporting the results. In keeping with other scoping reviews in which the research
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15 team is large and multi-disciplinary,²⁶ we did not undertake the optional step of consultation. To further
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17 outline the methodology, a completed PRISMA-ScR Checklist²⁷ for scoping reviews has been attached.
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19 Because scoping reviews seek to understand topics of significant complexity in a broad area, rather than
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21 synthesize only the best available evidence, a quality appraisal of included studies was not performed.²²
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25 **Patient and Public Involvement**

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28 A patient who was also a retired university professor (MS) with an education background was a
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30 member of the research team. He was recruited to provide a patient's perspective.²⁸ The lack of patient
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32 focus groups is recognized as a limitation of the study, however, the patient representative contributed
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34 actively to all phases of the scoping review from inception. He shared his experiences within the system
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36 and contributed to interpretation of the findings. We did not include patient focus groups in the
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38 consultation process for this scoping review.
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43 *2.2 Identifying the Research Question*

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46 In collaboration with knowledge users from the provincial Health Quality Council and health
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48 region in Saskatchewan, Canada, as well as decision makers from the Saskatchewan Ministry of Health,
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50 the team identified the following question as the focus for this scoping review: **What are the**
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52 **characteristics of interventions designed to build the capacity of hospitalized patients in addressing**
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54 **key health care priorities reported in the literature?**
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2.3 Identifying Relevant Studies

Following an initial scan of potentially relevant databases (including the Cochrane Database of Systematic Reviews), MEDLINE, Embase and CINAHL were selected for use in this review as having the best coverage of literature related to hospitals. A comprehensive electronic literature search was conducted by an experienced medical librarian (EW) in MEDLINE (through OVID), Embase (through OVID) and CINAHL Plus (through EBSCOhost) from inception to December 15, 2016 and updated August 31, 2017. Our search strategy included the following key terms and synonyms: acute care; hospitals; caregivers; family; and patient participation, empowerment, engagement or involvement. Please see Supplementary File 1 for the comprehensive search strategy in MEDLINE. The reference lists of studies were examined to identify additional relevant articles.

Literature search results were uploaded into Covidence™ Systematic Review Software²⁹ after removing duplicate references. This software provides a decision dashboard and annotation tool, as well as the capacity to create forms for screening and extracting data. Additional duplicates missed by the reference software were removed as identified. Studies were selected in two phases: a) title and abstract screening and b) full text screening/review.

2.4 Study Selection

Inclusion and exclusion criteria were developed based upon a preliminary literature review and the advice of knowledge users and decision-makers. In order to be included in this scoping review, the studies must have: a) taken place within a hospital setting (including inpatient rehabilitation); b) described or included a structured or systematic approach to building capacity of patients to participate in care, including organizational practices, bedside practices or access to information practices; c) included adult patients only and d) described the outcomes of the interventions from any one of the following stakeholder perspectives: patients and families; health care providers; health systems; or

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3 administrators/funders. All study designs were included, provided that the studies adhered to the
4 inclusion/exclusion criteria. We included only studies published in English for this scoping review, as this
5 was the primary language spoken by team members.
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10 Papers addressing interventions to build capacity in the following populations were excluded:
11 children and adolescents; community or home settings; oncology patients (because this group often
12 experiences rapid transitions between community, outpatient and inpatient settings) and Emergency
13 Department settings. We also excluded papers focused upon patient participation in research,
14 databases, quality improvement (e.g. patient advisory councils) or health care service re-design; or
15 patient needs, knowledge or activation assessments.
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24 Team training sessions for reviewers consisted of group screening of 20 titles. The inclusion and
25 exclusion criteria were pilot-tested during the training session resulting in minor revisions to enhance
26 the clarity of descriptors and improve inter-rater reliability. Following this training, titles and abstracts
27 were screened by two reviewers, one of whom was the PI (DG).²⁶ Discrepancies were resolved through
28 consensus between the reviewers.
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36 A second team training session for full text screening and review was held. Eight of the nine
37 team members participated in full text screening and review, with EP serving as an arbitrator. Two
38 researchers independently reviewed each of articles selected for full-text screening to ensure inclusion
39 criteria had been met. Discrepancies were discussed between the researchers to achieve consensus and
40 in one case, the dispute was resolved by the arbitrator.
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48 *2.5 Charting the Data*

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51 A standard data extraction form created using Microsoft Word (Supplementary File 2) was pilot-
52 tested in the team training session prior to data extraction. Use of this software, rather than the pre-set
53 categories in Covidence, allowed us flexibility in data extraction categories and entries. Pairs of team
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3 members were randomly assigned to extract data from 20 articles. Key characteristics extracted by the
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5 two reviewers for each article included: a) study identification (author, year of publication, setting,
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7 country); b) focus of the intervention; c) description of the intervention; d) study design and
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9 participants; and e) study findings. All extracted data from each pair of team members were reviewed
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11 and confirmed by DG.
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15 In order to categorize the focus of each article, reviewers initially coded each article according to
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17 the terms used by the authors (e.g. multidisciplinary goal setting). Two team members (DG and CH)
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19 then assigned each article to one of seven categories adapted from the AHRQ National Quality Strategy
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21 Priorities¹⁸ that reflected dominant themes of this corpus of literature: patient safety; care
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23 coordination; effective treatment; bedside nursing hand-overs; communication; care planning; and the
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25 care environment.
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29 Coding of BCT categories and techniques occurred following the data extraction. Each article
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31 was re-read by DG, MM and LN. BCT codes were assigned independently using the operational
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33 definitions provided by the BCT taxonomy v1¹⁹ and the supplementary BCT coding framework reported
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35 by Presseau et al.²⁰ There was no limit on the number of BCTs that could be identified. Discrepancies in
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37 BCT assignment were discussed and consensus achieved.
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41 *2.6 Collating, summarizing and reporting the results*

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44 A narrative approach was used to collate, summarize and report the data. Summary statistics
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46 were used to describe the number of studies by setting, country, year of publication, methods, focus
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48 and BCTs identified.
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51 **3. Results**

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3 A total of 9,899 articles (9,239 on December 15, 2016 and 660 in the search update on August
4 31, 2017) were identified after duplicates were removed through the search process (Figure 1).
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6 Following title and abstract screening, 503 remaining articles met our inclusion criteria and underwent
7 full-text screening. During the full-text assessment, 416 were excluded because they did not meet one
8 or more of the eligibility criteria (n= 319), did not report on a specific intervention (n= 36), or were
9 conference abstracts (n=61). See Figure 1 for the PRISMA Flow diagram.
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16 17 **3.1 Characteristics of included studies**

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20 Supplementary File 3 presents the summary of included studies (n=87).³⁰⁻¹¹⁷ Over half of these
21 studies originated in either the U.S. (n=32, 36.8%) or the U.K. (n=17, 19.5%). Fifteen (17.2%) came from
22 Scandinavian countries and eight from Australia (9.2%). Only five (5.7%) articles were published prior to
23 2000.
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30 **3.1.1 Study designs**

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32 The studies included were methodologically diverse. Of the 87 included articles, three (3.4%)
33 were randomized controlled trials examining outcomes of interventions designed to build patient
34 capacity to participate in care coordination⁴⁰, communication⁶⁶ and effective treatment.¹⁰⁹ Three
35 (3.4%) cluster randomized controlled trials were aimed at improving patient capacity to participate in
36 safety initiatives⁸², recognize deteriorating condition¹⁰⁶, and the care environment.¹¹⁵
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44 The remaining studies included quasi-experimental designs, case-controlled studies (including
45 the use of administrative data), interrupted time series, ethnographies, case studies, chart reviews and
46 pre- and post-test designs. Qualitative and mixed methods approaches (n=29, 33.3%) and cross-
47 sectional or pre- and post- interventions surveys (n=21, 24.1%) were used in over half of the included
48 studies.
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3.1.2 Patient populations

While a significant proportion of capacity-building interventions (e.g. safety, rapid response teams) were implemented across entire acute care hospitals, other studies were directed towards specific patient populations, such as critically ill (n=7, 8.0%)^{35, 52, 56, 71, 73, 85, 97}, geriatric (n=6, 6.9%)^{53, 78, 86, 92, 103, 113}, rehabilitation (n=9, 10.3%)^{48, 69, 70, 89, 97, 104, 108, 116, 117}, surgical (n=6, 6.9%)^{64, 72, 109, 112, 113} or psychiatric (n=8, 9.2%)^{34, 58, 68, 87, 95, 100, 101, 110} patients.

3.1.3 Outcomes

Positive outcomes were reported in two of the three randomized controlled trials^{40, 68} and two of the three cluster randomized controlled trials^{106, 115}. Failure to achieve key study objectives were reported in a number of the remaining studies.^{33, 50, 77, 82, 85, 87, 96, 100, 112} The remaining studies reported one or more positive outcomes associated with the intervention to build hospitalized patient capacity to engage in care.

3.2 Aspects of care addressed by capacity-building interventions

Interventions designed to build patients' capacity to participate were found to address seven key aspects of care in hospitals. These aspects of care included: patient safety (n=18; 20.7%); bedside nursing handovers (n=5; 5.7%); communication (n=25; 28.7%); care planning (n=12; 13.8%); modifications to the care environment to promote engagement (n=17; 19.5%); care coordination (n=5; 5.7%) and effective treatment (5; 5.7%).

The interventions focused on patient safety addressed a range of safety issues including: medications^{30, 39, 60, 77, 114}; falls^{30, 53, 69}; hand-washing^{30, 46, 47, 54, 84, 90}; surgical site identification³⁰; medical error⁸⁰; or patient reporting and action^{32, 77, 82, 88, 93, 98}. Eleven (12.6%) studies incorporated a form of information technology to build the capacity of patients to participate in care.

One-third of the included studies (n=25; 28.7%) reported interventions designed to enhance communication between patients and providers to promote participation in care. Examples included interventions designed to encourage interactions between patients, families and providers^{35, 44, 52, 71}, to provide a means by which patients or families could communicate their wishes or concerns^{74, 75, 81, 85} or to share clinical information with patients.^{33, 61, 66, 72, 97}

Multi-component programs aimed at enhancing the environment in which patient-and family-care was delivered accounted for 17 (19.5%) studies. These interventions often involved new models of care specifically aimed at promoting patient-centredness using multiple interventions, such as the adoption of new standards of care.⁷⁹

3.3 Behavior Change Techniques Identified to Build Patient Capacity to Participate in Care

Table 1 describes the types of behavior change techniques used to build capacity for each of the seven key aspects of care.

Table 1. Behavior Change Techniques Identified to Build Patient Capacity to Participate in Care (n=87)

Aspect of Care	References	BCT
Patient Safety (n=18)	30	Shaping knowledge Antecedents (adding objects to the environment)
	32	Antecedents (restructuring the physical and social environment; adding objects to the environment)
	39*	Antecedents (adding objects to the environment)
	46	Shaping knowledge Antecedents (adding objects to the environment)
	47	Shaping knowledge Antecedents (adding objects to the environment)
	53*	Antecedents (adding objects to the environment)
	54	Shaping knowledge Antecedents (adding objects to the environment)
	60	Antecedents (adding objects to the environment)
	67	Shaping knowledge

Aspect of Care	References	BCT
		Feedback and monitoring Repetition and Substitution (behavioral practice/ rehearsal)
	77	Shaping knowledge Antecedents (adding objects to the environment)
	80	Antecedents (restructuring social environment) Shaping knowledge Repetition and substitution Comparison of behavior (demonstration)
	82	Antecedents (adding objects to the environment) Feedback and monitoring
	84	Antecedents (adding objects to the environment) Feedback and monitoring Association (prompts and cues)
	88	Antecedents (adding objects) Feedback and monitoring
	90	Feedback and monitoring Shaping knowledge
	93	Antecedents (restructuring the social environment) Shaping knowledge
	98	Antecedents (adding objects to the environment) Shaping Knowledge Comparison of behavior (demonstration)
	114	Antecedents (restructuring the social environment)
Person- and Family-Centred Care: Bedside Nursing Handovers (n=5)	31	Shaping knowledge Antecedents (adding objects to the environment)
	37	Antecedents (restructuring the physical and social environments) Scheduled consequences
	76	Antecedents (restructuring the social environment)
	91	Antecedents (restructuring social environment)
	105	Shaping knowledge Antecedents (restructuring social environment; adding objects to the environment)
Person- and Family-Centred Care: Communication (n=25)	33*	Antecedents (adding objects to the environment)
	35	Shaping knowledge Social Support
	44*	Goals and planning Antecedents (restructuring the social environment; adding objects to the environment)
	48	Goals and planning

Aspect of Care	References	BCT
	50	Feedback and monitoring Antecedents (Adding objects to the environment)
	52	Antecedents (restructuring social environment)
	55*	Antecedents (restructuring the social environment; adding objects to the environment)
	61*	Antecedents (restructuring the social environment; adding objects to the environment)
	62	Shaping knowledge Antecedents (adding objects to the environment)
	63*	Antecedents (adding objects to the environment)
	65	Feedback and monitoring Antecedents (restructuring social environment; adding objects to the environment)
	66*	Antecedents (adding objects to the environment) Shaping knowledge Feedback and monitoring
	68	Shaping knowledge Repetition and Substitution (behavioral practice) Feedback and monitoring
	71	Shaping knowledge Antecedents (restructuring the social environment; adding objects to the environment)
	72	Shaping knowledge Antecedents (adding objects to the environment)
	74	Feedback and monitoring Antecedents (restructuring the social environment; adding objects to the environment)
	75	Feedback and monitoring Antecedents (restructuring the social environment; adding objects to the environment)
	81	Goals and Planning Antecedents (adding objects to the environment)
	85	Shaping knowledge Antecedents (restructuring the social environment)
	86	Antecedents (restructuring the social environment)
	94*	Shaping knowledge Antecedents (adding objects to the environment)
	97	Shaping knowledge Antecedents (restructuring the social environment; adding objects to the environment)
	103	Shaping Knowledge Antecedents (adding objects to the environment) Goals and Planning

Aspect of Care	References	BCT
		Feedback and monitoring
	107	Antecedents (adding objects to the environment) Goals and Planning
	110	Antecedents (restructuring the social environment)
Person- and Family-Centred Care: Care Planning (n=12)	42*	Feedback and monitoring Antecedents (adding objects to the environment)
	45	Goals and planning Antecedents (restructuring the social environment)
	49	Goals and planning Antecedents (restructuring the social environment)
	51	Goals and Planning
	56*	Antecedents (adding objects to the environment)
	73	Antecedents (restructuring the social environment)
	96	Antecedents (restructuring the social environment)
	102	Antecedents (restructuring the social environment)
	111	Antecedents (restructuring the social environment) Goals and Planning
	112	Antecedents (restructuring the social environment) Feedback and monitoring
	116	Goals and Planning Antecedents (restructuring the social environment)
117	Goals and Planning Antecedents (restructuring the social environment) Social support	
Person- and Family Centred Care: Care Environment Programs (n=17)	34	Goals and Planning Antecedents (restructuring the social environment)
	36	Goals and planning Feedback and monitoring Antecedents (restructuring the physical and social environments)
	58	Feedback and monitoring (Self-monitoring of behavior) Antecedents (restructuring the social environment)
	59	Antecedents (restructuring the social environment; adding objects to the environment) Social support
	64	Shaping knowledge Natural consequences
	67	Social support Antecedents (restructuring the social environment)

Aspect of Care	References	BCT
	78	Shaping knowledge Antecedents (adding objects to the environment) Social support
	79	Antecedents (restructuring the social environment; adding objects to the environment) Goals and Planning
	87	Social Support Antecedents (Restructuring the social environment)
	92	Goals and Planning Antecedents (restructuring the social environment)
	99	Antecedents (restructuring the social environment)
	100	Antecedents (restructuring the physical and social environments; adding objects to the environment)
	101	Antecedents (restructuring the physical and social environments; adding objects to the environment)
	104	Goals and Planning Antecedents (restructuring the social environment; adding objects to the environment)
	108	Antecedents (restructuring the social environment)
	113	Shaping knowledge Antecedents (restructuring the social environment)
	115	Shaping knowledge Feedback and monitoring
Care Coordination (n=5)	38	Shaping knowledge Antecedents (adding objects to the environment)
	40	Shaping knowledge Antecedents (adding objects to the environment) Feedback and monitoring Natural consequences Goals and planning
	41	Shaping knowledge Antecedents (adding objects to the environment) Natural consequences Goals and planning
	43	Antecedents (adding objects to the environment) Regulation
	57	Shaping knowledge Identity
Effective Treatment (n=5)	70	Shaping knowledge Feedback and monitoring Repetition and Substitution Regulation
	83	Antecedents (restructuring the social environment; adding objects to the environment)

Aspect of Care	References	BCT
		Goals and planning Repetition and substitution Regulation
	89	Antecedents (adding objects to the environment) Feedback and monitoring Shaping knowledge
	106	Shaping knowledge Antecedents (restructuring the social environment; adding objects to the environment)
	109	Antecedents (restructuring the social environment) Social support Regulation

* Studies that included some information technology used by patients and/or families.

Overall, the use of antecedents was the most frequently identified category of BCT (n=76, 87.3%). This category includes: restructuring the physical environment; restructuring the social environment; avoidance/reducing exposure to cues for the behavior; distraction; adding objects to the environment and body changes (e.g. strength training).¹⁹ Antecedents can be used to “set the stage” for desired responses. Because of the frequency of identification of the category of antecedents, this category of BCT was further coded into the specific techniques employed. Adding objects to the environment was identified as an antecedent in a total of 48 (55.2%) studies. Examples of adding objects to promote patient participation in care included the use of instructional videos^{e.g. 62, 99} and introduction of technologies such as tablets to share information.³¹ Fifteen (17.2%) of these studies simultaneously added objects in conjunction with restructuring the social environment. This is illustrated by Dykes et al.’s⁵⁵ multifaceted intervention involving a patient-centred care and engagement program and web-based technology, including a safety checklist and a messaging platform used by patients and care partners to view health information, participate in their care plan and communicate with care providers.

Studies that changed the social environment (n=41, 47.1%) to facilitate patient participation in care were classified as having employed the BCT of restructuring the social environment [BCT]. Following the BCT coding rules of Pesseau et al.²¹, we included in this category studies which described

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3 interventions in which someone new (patients, family member or provider) took on care, someone was
4 added to take on new care responsibilities or someone was added to the team, or care was shifted
5 outside the team. An example of changes made to the social environment was the adoption of a new
6 model of care providing flexible family visiting, supporting carer involvement and improving
7 partnerships between carers and the health care team.⁵⁹

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15 Five studies (5.7%) were identified as making simultaneous changes to both the social and
16 physical environments. An instance of changing both the social and physical environment was reported
17 by Rise et al.¹⁰⁰, who established a new patient education center as one component of an intervention,
18 along with appointing staff who could be contacted by families. No studies were identified as
19 restructuring only the physical environment.

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27 Shaping knowledge was identified as a BCT in 33 studies (37.9%). This BCT is illustrated in the
28 study by Langer et al.⁸⁰ in which clinicians were brought together with patients and families in a
29 collaborative learning experience focused on developing patient-centred medical error disclosure
30 communication skills. A second example of shaping knowledge was the use of the PINK (Participate; Be
31 informed; Notice and be alert; Know what you can do) video⁴⁶ with the specific goal of educating
32 patients in the prevention of medical errors.

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41 Feedback and monitoring were identified in 20 studies (23.0%). An example is Coleman et al.'s
42 ⁴⁰Care Transition program, in which patients monitored and responded to changes in their health
43 conditions as a component of the intervention. Goals and planning were coded in 19 studies (21.8%). An
44 example of goals and planning involved goal setting meetings between the patient, family, and
45 multidisciplinary team.⁴³ Other categories of BCTs identified in the studies included: social support
46 (n=7; 8.0%); repetition and substitution (n=5; 5.7%); regulation (n=4; 4.6%); natural consequences (n=3;
47 3.4%); and comparison of behavior (n=2; 2.3%). The BCTs of association, identity and scheduled
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3 consequences were identified in one study each. Categories of BCT not identified in any of the included
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5 studies were reward and threat, self-belief and covert learning.
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8 In the majority of studies (n=69; 79.3%), the use of multiple categories of BCT as part of the
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10 capacity-building intervention could be identified. In studies where only a single BCT was identified,
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12 restructuring the social environment ^{52, 73, 76, 86, 91, 96, 99, 101, 108, 110} occurred most frequently (n=10),
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14 although adding objects to the environment ^{33, 39, 53, 56, 60, 63}, and goals and planning ^{48, 51} were also
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16 employed as BCTs.
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19 20 **4.0 Discussion and Conclusion** 21

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23 This scoping review has identified seven aspects of care in which efforts to build capacity of
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25 hospitalized patients to participate in care were reported: patient safety; care coordination; effective
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27 treatment; bedside nursing hand-overs; communication between patients and providers; inpatient care
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29 planning; and the overall care environment. Both large-scale (hospital-wide) and population- and unit-
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31 specific interventions were reported. Descriptions of these interventions in the included studies
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33 provided sufficient detail to allow for classification of the key BCTs utilized within each intervention. The
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35 use of antecedents (e.g. adding objects to the environment or restructuring the social and/or physical
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37 environment) was the most frequently identified BCT category across all included studies. In 60 per cent
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39 of the studies, multiple BCTs could be identified.
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44 In keeping with the nature of a scoping review, the articles included in this scoping review were
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46 heterogeneous in terms of the aspect of care addressed, aims and methodological rigor. The strength of
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48 evidence was generally weak to very weak, thus limiting the interpretation and application for wider
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50 clinical practice. This heterogeneity limited our ability to draw conclusions about the effectiveness of the
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52 interventions. Quality appraisal was not undertaken and, as previously identified, articles were limited
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54 to English language only and did not include grey literature. Specific details of interventions were not
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3 always provided in the publications and it is possible that some BCTs used could not be accurately
4 identified by the three reviewers who classified and achieved consensus on the BCTs identified. While
5 our search strategy was limited to MEDLINE, Embase and CINAHL, it would be helpful to consider the
6 inclusion of additional databases in future reviews. Although we searched the Cochrane database and
7 did not find relevant systematic reviews, new reviews may be available in the future. As research
8 addressing patient participation in care becomes increasingly more sophisticated, future reviews may
9 focus on specific aspects of care such as safety for defined groups of patients.
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19 Reviews are increasingly seeking to identify the BCTs used in a range of interventions ^{e.g., 118-120} in
20 order to better understand the content of interventions and the underlying reasons for the outcomes
21 associated with interventions. Adding objects to the environment was identified as the most frequently
22 used BCT intervention in this scoping review, in keeping with the findings of Presseau et al. ²¹ Depending
23 on the nature of the publication and the intervention, more detailed descriptions of interventions were
24 available for some studies compared to others. Attempts to build capacity for patients to participate in
25 care are, at their core, social in nature, and particular care should be taken to describe how the social
26 environment facilitates performance of the desired behavior or creates barriers to behaviors excluding
27 patients or families from participation.
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40 Interventions aimed at building the capacity of hospitalized patients to participate more fully in
41 care require the use of complex interventions, especially as patient behavior cannot change
42 independently of provider behavior and health care system attributes. Genuine engagement of patients
43 in care will require a re-alignment of long-standing power imbalances between patients, providers and
44 the health care system, resulting in significant changes in behavior at many levels. ¹²¹ The participation
45 of a patient representative on this team examining the issue of patient participation proved to be
46 extremely helpful. This individual participated in all aspects of this review, from defining the research
47 question, screening and selection of included studies and data extraction. He provided key insights into
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3 the interpretation of the results from the perspective of an end user of the health care system. This
4 individual reported that participation in this process gave him a sense of empowerment that he was
5 influencing the knowledge base of patient care. He also noted that the process provided him with
6 knowledge to better critique the delivery of health services. The recent GRIPP2 reporting checklist on
7 improving the reporting of patient and public involvement in research ²⁶ provides important guidance on
8 this issue. We would recommend that future studies include patient focus groups as a means of
9 expanding patient input.
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19 The rapidly evolving interest in developing interventions promoting the participation of
20 hospitalized patients in care was demonstrated by the additional 660 articles that were published over
21 the eight-month period between the time of the initial search and the search update. Given the growing
22 corpus of research, this review provides an important synthesis of what has been reported to build the
23 capacity of hospitalized patients to participate in care. This review aimed also to classify the “active
24 ingredients” underpinning the interventions by using the BCT Taxonomy. ¹⁹ The findings generated
25 through this synthesis will provide an evidentiary basis for the development of, and future research
26 related to, tailored approaches to building patient capacity to participate in care.
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38 Figure Legend

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41 Figure 1: Prisma Screening Flowchart
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49

50
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3 years of beginning the submitted work that could inappropriately influence, or be perceived to
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5 influence, their work.
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7
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9
10 DG coordinated the project and is the guarantor. MM, LN, MS, EH, TR, CH, EP and DG screened the
11
12 studies and contributed to the interpretation of findings. DG, MM and LN extracted the data. DG drafted
13
14 and all authors critically reviewed and approved the revised manuscript.
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18 Data sharing statement: All publications in this review have been duly referenced and are publicly
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42
43
44
45
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49
50
51
52
53
54
55
56
57

References

1. Groene O. Patient-centredness and quality improvement efforts in hospitals: rationale, measurement, implementation. *Int J Qual Health Care* 2011;23:531-537.
2. Lombarts MJ, Rupp I, Vallejo P, Sunol R, Klazinga NS. Application of quality improvement strategies in 389 European hospitals: results of the MARQuIS Project. *BMJ Qual Saf* 2008;18(Suppl1):i28-i37.
3. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff* 2013;32(2):223-231.
4. Clancy CM. Patient engagement in health care. *Health Serv Res* 2011;46:389-393.
5. World Health Organization. Patient Engagement: Technical Series on Safer Primary Care 2016. Available at <http://apps.who.int/iris/bitstream/handle/10665/252269/9789241511629-eng.pdf;jsessionid=2D38D96403E594B7509C1F6079358A6A?sequence=1>.
6. Hibbard JH, Mahoney ER, Stock R et al. Do increases in patient activation result in improved self management behaviors? *Health Serv Res* 2007;42:1443-63.
7. Mosen DM, Schmittiel J, Hibbard et al. Is patient activation associated with outcomes of care for adults with chronic conditions? *J Ambul Care Manage* 2007;30:21-9.
8. Weingart SN, Zhu J, Chiapetta L et al. Hospitalized patient participation and its impact on quality of care and patient safety. *Int J Qual Health Care* 2011;23:269-77.
9. Epstein RM, Franks P, Shields CG et al. Patient-centred communication and diagnostic testing. *Ann Fam Med* 2005;3:415-21.
10. Bertakis KD, Azari R. Patient-centred care is associated with decreased health care utilization. *J Am Board Fam Med* 2011;24:229-39.

- 1
2
3 11. Charmel P, Frampton S. Building the business case for patient-centred care. *Healthc Financ Manage*
4
5 2008;62;80-5.
6
- 7
8 12. Aronson PL, Yau J, Helfaer MA et al. Impact of family presence during pediatric intensive care rounds
9
10 on the family and medical team *Pediatrics* 2009;24:1119-25.
11
- 12 13. Balik B, Conway J, Zipperer L, Watson J. Achieving an exceptional patients and family experience of
13
14 inpatient hospital care. IHI Innovation Series white paper. Cambridge, MASS: Institute for Healthcare
15
16 Improvement, 2011. Elements of hospital-based patient- and family-centred care
17
- 18 14. Gausvik C, Lautar A, Miller L, et al. Structured nursing communication on interdisciplinary acute care
19
20 teams improves perceptions of safety, efficiency, understanding of care plans and team work as well as
21
22 job satisfaction. *J Multidisc Healthcare* 2015;8:337.
23
- 24 15. Batalden M, Batalden P, Margolis P, Armstrong G, Opipari-Arrigan L, Hartung, H. Coproduction of
25
26 healthcare service. *BMJ Qual Saf* 2016; 25: 509-17. doi: 10.1136/bmjqs-2015-004315.
27
- 28 16. Gagliardi AR, Legare F, Brouwers MC, Webster F, Badley E, Straus S. Patient-mediated knowledge
29
30 translation (PKT) interventions for clinical encounters: a systematic review. *Implem Sci* 2016;11:26.17.
31
32
- 33 17. Herrin J, Harris KG, Kenward K, Hines S, Joshi MS, Frosch DL. Patient and family engagement: a
34
35 survey of US hospitals. *BMJ Qual Saf* 2015;0: 1-8.
36
37
- 38 18. Agency for Healthcare Research and Quality. 2015 National healthcare quality and disparities report
39
40 and 5th anniversary update on the National Quality Strategy: Priorities of the National Quality Strategy.
41
42 Available at <https://www.ahrq.gov/research/findings/nhqdr/nhqdr15/priorities.html>.
43
44
- 45 19. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W et al. The Behavior Change
46
47 Technique Taxonomy (v1) of 93 hierarchically clustered techniques: Building an international consensus
48
49 for the reporting of behavior change interventions. *Ann Behav Med* 2013;46:81-92.
50
51
- 52 20. National Institute for Health and Care Excellence (NICE). Behaviour change: individual approaches.
53
54 <https://www.nice.org.uk/guidance/ph49/chapter/7-glossary>.
55
56
57

- 1
2
3 21. Pesseau J, Ivers NM, Newham JJ, Knittle K, Danko KJ, Grimshaw JM. Using a behavior change
4 techniques taxonomy to identify active ingredients within trials of implementation interventions for
5 diabetes care. *Implem Sci* 2015;10:55
6
7
8
9
10 22. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *Int J Soc Res Meth*
11 2005;8:19-32.
12
13
14 23. Goodridge D, Henry C, Watson E, McDonald M, New L, Harrison EL, Scharf M, Penz E, Campbell S,
15 Rotter T. Structured approaches to promote patient and family engagement in treatment in acute care
16 hospital settings: protocol for a systematic scoping review. *Syst Rev* 2018;7:35.
17
18
19
20 24. Colquhoun HL, Levac D, O'Brien KK, Straus S, Tricco AC, Perrier , Kastner M, Moher D. Scoping
21 reviews: time for clarity in definition, methods and reporting. *J Clin Epidemiol* 2014;67:1291-4.
22
23
24 25. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology, *Implem Sci*
25 2010;5:69.
26
27
28
29 26. Daudt HML, van Mossel C, Scott SJ. Enhancing the scoping study methodology: a large, inter-
30 professional team's experience with Arksey and O'Malley's framework. *BMC Med Res Methodol*
31 2013;13:48.
32
33
34 27. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping
35 Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med* 2018,169:467–473. doi:
36 10.7326/M18-0850.
37
38
39 28. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. GRIPP2 reporting checklists:
40 tools to improve reporting of patient and public involvement in research. *BMJ* 2017;358:j3453.
41
42
43 29. Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia. Available
44 at <http://www.covidence.org>.
45
46
47 30. Anthony R, Miranda F, Mawji Z, Cerimele R, Davis R, Lawrence S. John M. Eisenberg Patient Safety
48 Awards. The LVHNN patient safety video: patients as partners in safe care delivery. *Joint Comm J Qual*
49 *Saf* 2003;29:640-645.
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 31. Ayana M, Pound P, Ebrahim S. The views of therapists on the use of a patient-held record in the care
4 of stroke patients, *Clin Rehab* 1998;12:328-337.
5
6
7 32. Baird SK, Turbin LB. Condition Concern: an innovative response system for enhancing hospitalized
8 patient care and safety. *J Nurs Care Qual* 2011;26(3):199-207.
9
10
11 33. Baysari MT, Adams K, Lehnbohm EC, Westbrook JI, Day RO. iPad use at the bedside: a tool for
12 engaging patients in care processes during ward rounds? *Int Med J* 2014;44(10):987-990.
13
14
15 34. Berger JL. Incorporation of the tidal model into the interdisciplinary plan of care – a program quality
16 improvement project. *J Psychiatr Men Health Nurs* 2006;12:464-467.
17
18
19 35. Black P, Boore HRP, Parahoo K. The effect of nurse-facilitated family participation in the
20 psychological care of the critically ill patient. *J Adv Nurs* 2011; 76(5):1091-1101.
21
22
23 36. Boltz M, Chippendale T, Resnick B, Galvin JE. Testing family-centred, function-focused care in
24 hospitalized persons with dementia. *Neurodegener Dis Manage* 2015;5(3):203-215.
25
26
27 37. Bradley S, Mott S. Adopting a patient-centred approach: an investigation into the introduction of
28 bedside hand-over to three rural hospitals. *J Clin Nurs* 2014;23:1927-1936.
29
30
31 38. Bull MJ, Hansen HE, Gross CR. A professional-patient partnership model of discharge planning with
32 elders hospitalized with heart failure. *Appl Nurs Res* 2000;13:19-28.
33
34
35 39. Buning AW, Klopotoska JE, Duyvendak M, Engelen LJLP, Arts J. Patient empowerment through the
36 provision of a mobile application for medication reconciliation: a proof of concept study. *BMC*
37 *Innovations* 2016;2:152-157.
38
39
40
41 40. Coleman EA, Parry C, Chalmers S, Min SJ. The care transitions intervention: results of a randomized
42 controlled trial. *Arch Int Med* 2006;166:1822-9.
43
44
45 41. Coleman EA, Smith JD, Parry C, Chalmers S, Min SJ. Preparing patients and caregivers to participate
46 in care delivered across settings: The care transitions intervention. *J Am Ger Soc* 2004;52:1817-1825.
47
48
49 42. Cook DJ, Manning DM, Holland DE, Prinsen SK, Rudzik SD, Roger VL, Deschamps C. Patient
50 engagement and self-reported outcomes in surgical recovery: effectiveness of an e-health platform. *J*
51 *Am Coll Surg* 2013;217:648-655.
52
53
54
55
56
57
58
59
60

- 1
2
3 43. Cordasco KM, Asch SM, Bell DS, Guterman JJ, Gross-Schulman S, Ramer L et al. A low-literacy
4 education tool for safety-net hospital patients. *Am J Prev Med* 2009;37:S209-S216.
5
6
7 44. Dalal AK, Dykes PC, Collins S, Lehmann LS, Ohashi Km Rozenblum R et al. A web based, patient-
8 centred toolkit to engage patients and caregivers in the acute-care setting: a preliminary evaluation. *J*
9 *Am Med Inform Assoc* 2016;23:80-87.
10
11
12 45. Dalton C, Farrell R, De Souza A, Wujanto E, McKenna-Slade A, Thompson S et al. Patients inclusion in
13 goal setting during early inpatient rehabilitation after acquired brain injury. *Clin Rehab* 2012;26:165-173.
14
15
16 46. Davis RE, Pinto A, Sevdalis N, Vincent C, Massey R, Darzi A. Patients' and professionals' attitudes
17 towards the PINK patient safety video. *J Eval Clin Pract* 2012;18:848-853
18
19
20 47. Davis RE, Sevdalis N, Pinto A, Darzi A, Vincent CA. Patients' attitudes towards patient involvement in
21 safety interventions: results of two exploratory studies. *Health Exp* 2013;16:163-176.
22
23
24 48. D'Cruz K, Unsworth C, Roberts K, Morarty J, Turner-Stokes L, Wellington-Boyd A et al. Engaging
25 patients with moderate to severe acquired brain injury in goal setting. *Int J Ther Rehab* 2016;23:20-31.
26
27
28 49. Dev R, Coulson L, Del Fabbro E, Palla SL, Yennurajalingam S, Rhondali W, Bruera E. A prospective
29 study of family conferences: Effects of patient presence on emotional expression and end-of-life
30 discussions. *J Pain Sympt Manag* 2013;46:536-545.
31
32
33 50. Dijkstra R, Braspenning J, Grol R. Empowering patients: how to implement a diabetes passport in
34 hospital care. *Pat Ed Couns* 2002;47:173-177.
35
36
37 51. Donnelly SM, Carter-Anad J, Cahill S, Gilligan R, Mehigan B, O'Neill D. Multiprofessional views on
38 older patients' participating in care planning meetings in a hospital context. *Practice Soc Work Act*
39 2013;25;121-138.
40
41
42 52. Doyle CJ, Post H, Burney RE, Maino J, Keefe M, Rhee KJ et al. Family participation during
43 resuscitation: an option. *Ann Emerg Med* 1987;16:673-675.
44
45
46 53. M. Duckworth, E. Leung, T. Fuller, J. Espares, B. Couture, F. Chang, A.C. Businger, S. Collings, A. Dalal,
47 A. Fladger, J.L. Schnipper, K.O. Schnook, D.W. Bates, P.C. Dykes. Nurse, patient and care partner
48 perceptions of a personalized safety plan screensaver. *J. Gerontol. Nurs* (2017) 43:15-22.
49
50
51 54. Duncan C. An exploratory study of patients' feeling about asking healthcare professionals to wash
52 their hands. *J Ren Care* 2007;33:30-34.
53
54
55
56
57
58
59
60

- 1
2
3 55. Dykes PC, Rozenblum R, Dalal A, Massaro A, Chang F, Clements M, et al. Prospective evaluation of a
4 multifaceted intervention to improve outcomes in intensive care: The Promoting Respect and Ongoing
5 Safety through Patient Engagement Community and Technology Study. *Crit Care Med* 2017; 5:e806-
6 e813.
7
8
9
10 56. Dykes PC, Stade D, Chang F, Dalal A, Getty G, Kandala R et al. Participatory design and development
11 of a patient-centred toolkit to engage hospitalized patients and their care partners in their plan of care.
12 *AMIA Symposium* 2014:486-495.
13
14
15 57. Dystad DN, Storm M. Interprofessional simulation to improve patient participation in transitional
16 care. *Scand J Car Sci* 2017;31:273-284.
17
18
19 58. Ellegaard T, Bliksted V, Lomborg K, Mehlsen M. Use of patient-controlled psychiatric hospital
20 admissions: patients' perspective. *Nord J Psychiatry* 2017;71:370-77.
21
22
23 59. Ewart L, Moore J, Gibbs C, Crozier K. Patient- and family-centred care on an acute adult cardiac ward.
24 *Brit J Nurs* 2013;23:213-218.
25
26
27 60. Fredericks JE, Bunting RF. Implementation of a patient-friendly medication schedule to improve
28 patient safety within a healthcare system. *J Healthcare Risk Manag* 2010;29:22-27.
29
30
31 61. Furness ND, Bradford OJ, Paterson MP. Tables in trauma: mobile computing platforms to improve
32 patients understanding and experience. *Orthoped* 2013;36:205-208.
33
34
35 62. Gillespie BM, Chaboyer W, Sykes M, O'Brien J, Brandis S. Development and pilot-testing of a patient-
36 participatory pressure ulcer prevention care bundle. *J Nurs Care Qual* 2014;29:74-82.
37
38
39 63. Gill SD, Redden-Hoare J, Dunning TL, Hughes AJ, Dolley PJ. Health services should collect feedback
40 from inpatients at the point of service: opinions from patients and staff in acute and subacute facilities.
41 *Int J Qual Healthc* 2015;27:507-512.
42
43
44 64. Gillis C, Gill M, Marlett N, Mackean G, Germann K, Gilmour K et al. Patients as partners in Enhanced
45 Recovery after Surgery: a qualitative patient-led study. *BMJ Open* 2017;7;no pagination.
46
47
48 65. Greenhouse PK, Kuzminsky B, Martin SC, Merryman T. Emergency calling a condition h(elp): one
49 facility gives patients and families the ability to summon a rapid response team. *Am J Nurs* 2006;106:63-
50 66.
51
52
53
54
55
56
57
58
59
60

- 1
2
3 66. Greysen SR, Khanna RR, Jacolbia R, Lee HM, Auerbach AD. Tablet computers for hospitalized
4 patients: a pilot study to improve patient engagement. *J Hosp Med* 2014;9:396-399.
5
6
7 67. Grieco AJ, Garnett SA, Glassman KS, Valoon PL, McClure ML. New York University Medical Center's
8 Cooperative Care Unit: Patient education and family participation during hospitalization – the first ten
9 years. *Pat Ed Couns* 1990;15:3-15.
10
11
12 68. Hamann J, Mendel R, Meier A, Asani F, Pausch E, et al. "How to Speak to your Psychiatrist": Shared
13 decision-making training for patients with schizophrenia. *Psych Serv* 2011;62:1218-1221.
14
15
16 69. Hill AM, McPhail SM, Francis-Cload-J, Waldron N, Etherton-Beer C, Flicker L, et al. Educators'
17 perspectives about how older patients can engage in a falls prevention education programme: a
18 qualitative process outcome. *BMJ Open* 2015;5(12)(no pagination)
19
20
21 70. Hirano Y, Maeshima S, Osawa, Nishio D, Takeda K, Baba M et al. The effect of voluntary training with
22 family participation on early home discharge in patients with severe stroke at a convalescent
23 rehabilitation hospital. *Eur Neurol* 2012;68:221-228..
24
25
26 71. Huffines M, Johnson KL, Naranjo LS, Lissauer ME, Fishel MA, D'Angelo SM. Participation in decision-
27 making in an intensive care unit. *Crit Care Nurs* 2013;33:56-69.
28
29
30 72. Ivarsson B, Larsson S, Luhrs C, Sjoberg T. extended written pre-operative information about possible
31 complications at cardiac surgery – do patients want to know? *Eur J Cardio-Thorac Surg* 2005;28:407-14.
32
33
34 73. Jacobowski NL, Girard TD, Mulder JA, Ely EW. Communication in critical care: family rounds in the
35 intensive care units. *Am J Crit Care* 2010;19:421-430.
36
37
38 74. Jangland E, Carlsson M, Lundgren E, Gunningberg L. The impact of an intervention to improve
39 patient participation in a surgical care unit: a quasi-experimental study. *Int J Nurs Stud* 2012;49:528-538.
40
41
42 75. Jangland E, Gunningberg L. Improving patient participation in a challenging context: a 2-year
43 evaluation study of an implementation project. *J Nurs Manag* 2017;25:266-275.
44
45
46 76. Jeffs L, Beswick S, Acott A, Simpson E, Cardoso R, Campbell H et al., Patients' views on bedside
47 handover. *J Nurs Care Qual* 2014;29:149-154.
48
49
50 77. Kutty S, Weil S. "Your health care – be involved": the evaluation of a provincial safety tips initiative.
51 *Healthc Quar* 2006;9:102-107.
52
53
54
55
56
57
58
59
60

- 1
2
3 78. Laitinen-Junkkari P, Merilainen P, Sinkkonen S. Informal caregivers' participation in elderly-patient
4 care: an interrupted time series study. *Int J Nurs Pract* 2001;7:199-213.
5
6
7 79. Lakeman R. Practice standards to improve the quality of family and carer participation in adult
8 mental health: an overview and evaluation. *Int J Ment Health Nurs* 2008;17:44-56.
9
10
11 80. Langer T, Martinez W, Browning D, Varrin P, Sarnoff Lee B, Bell SK. Patients as teachers in patient
12 safety: a new interprofessional educational model for collaborative learning about medical error
13 disclosure and prevention. *J Gen Int Med* 2015;30:S504.
14
15
16
17 81. Lankarani-Fard A, Knapp H, Lorenz KA, Golden JF, Taylor A, Feld JE, et al. Feasibility of discussing end-
18 of-life goals with inpatients using a structured, conversational approach: the go-wish care game. *J Pain*
19 *Sympt Manag* 2010;39:637-43.
20
21
22
23 82. Lawton R, O'Hara JK, Sheard L, Armitage G, Cocks K, Buckley H et al. Can patient involvement
24 improve patient safety? A cluster randomized control trial of the Patient Reporting and Action for a Safe
25 Environment (PRASE) intervention. *BMJ Qual Saf* 2017;26:622-631.
26
27
28
29 83. Lean M, Leavey G, Killaspy H, Green N, Harrison I, Cook S et al. Barriers to the sustainability of an
30 interventions designed to improve patient engagement within NHS mental health rehabilitation units: a
31 qualitative study nested within a randomized controlled trial. *BMC Psychiat* 2015; 15: (no pagination)
32
33
34
35 84. Lent V, Eckstein EC, Cameron AS, Budavich R, Eckstein BC, Donskey CJ. Evaluation of patient
36 participation in a patient empowerment initiative to improve hand hygiene practices in a Veterans
37 Affairs medical center. *Am J Inf Contr* 2009;37:117-120.
38
39
40
41 85. Leske JS, McAndrew NS, Brasel KJ, Feetham S. Family presence during resuscitation after trauma. *J*
42 *Trauma Nurse* 2017;24;85-96.
43
44
45
46 86. Lindberg E, Persson E, Horberg U, Ekeburgh M. Older patients' participation in team meetings – a
47 phenomenological study from the nurses' perspective. *Int J Qual Stud Health Well-being*
48 2013;8;10.3402/qhw.v8i0.21908
49
50
51
52 87. Livingston JD, Nijdam-Jones A, Lapsley S, Calderwood C, Brink J. Supporting recovery by improving
53 patient engagement in a forensic mental health hospital: results from a demonstration project. *J Am*
54 *Psychiatr Nurs Assoc* 2013;19:132-145.
55
56
57
58
59
60

- 1
2
3 88. Louch G, O'Hara J, Mohammed MA. A qualitative formative evaluation of a patient-centred patient
4 safety intervention delivered in collaboration with hospital volunteers. *Health Expect* 2017;15:15.
5
6
7 89. Martinez-Velilla N, Guerrues-irisarri M, Ibanez-Beroia B, Gil-Cabanas J, Richarte-Carcia A, Idoate-
8 Saralegui F et al. An exercise program with patients' involvement and family support can modify the
9 cognitive and affective trajectory of acutely hospitalized older medical patients: a pilot study. *Aging Clin*
10 *Exp Res* 2016;28:483-490.
11
12
13
14 90. McGuckin M, Waterman R, Storr J, Bowler ICJW, Ashby M, Topley K et al. Evaluation of a patient-
15 empowering hand hygiene program in the UK *J Hosp Inf* 2001;48:222-227.
16
17
18 91. McMurray A, Chaboyer W, Wallis M, Johnson J, Gehrke T. Patients perspectives of bedside nursing
19 handover. *Collegian* 2011;18:19-26.
20
21
22 92. Nyborg I, Kvigne K, Danbolt LJ, Kirkevold M. Ambiguous participation in older hospitalized patients:
23 gaining influence through active and passive approaches – a qualitative study. *BMC Nurs*;15:50.
24
25
26 93. Odell M, Gerber K, Gager M. Call 4 concern: patient and relative activated critical care outreach. *Br J*
27 *Nurs* 2010;19:1390-1395.
28
29
30 94. O'Leary KJ, Lohman ME, Culver E, Killarney A, Smith GR, Liebovitz DM. The effect of tablet computers
31 with a mobile patient portal application on hospitalized patients' knowledge and activation. *J Am Med*
32 *Inform Assoc* 2016;23:159-165.
33
34
35 95. Olso TM, Gudde CB, Moljord IEO, Evensen GH, Antonsen DO et al. More than just a bed: mental
36 health service users' experiences of self-referral admission. *Int j Ment Health Sys* 2016;10: (no
37 pagination).
38
39
40
41 96. Paradis E, Leslie M, Gropper MA. Interprofessional rhetoric and operational realities: an
42 ethnographic study of rounds in four intensive care units. *Adv Health Sci Educ* 2016;21:735-48.
43
44
45 97. Pegg PO, Auerbach SM, Seel RT, Buenaver LF, Keisler DJ, Plybon LE. The impact of patient-centred
46 information on patients' treatment satisfaction and outcomes in traumatic brain injury rehabilitation.
47 *Rehab Psychol* 2005;50:366-374.
48
49
50
51 98. Pinto A, Vincent C, Darzi A, Davis R. A qualitative exploration of patients' attitudes towards the
52 "Participate Inform Notice Know' (PINK) patient safety video *Int J Qual Health Care* 2013; 25:29-34.
53
54
55
56
57
58
59
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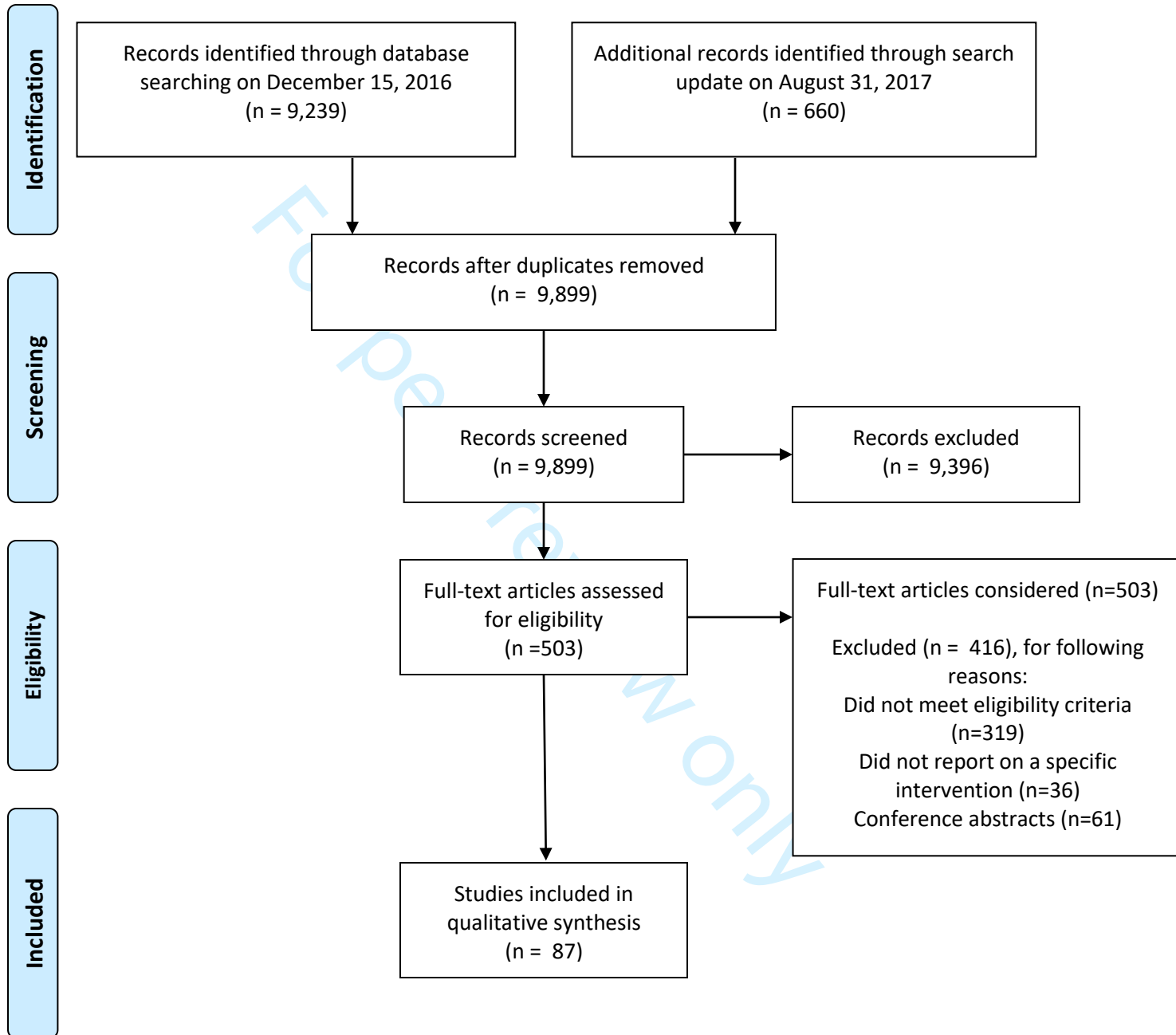
- 1
2
3 99. Pomey MP, Ghadiri DP, Karazivan P, Fernandez N, Clavel N. Patients as partners: a qualitative study
4 of patients' engagement in their health care. PLoS ONE 2015;10: (no pagination) e0122499.
5
6
7 100. Rise MB, Grimstad H, Solbjor M, Steinsbekk A. Effect of an institutional development plan for user
8 participation on professionals' knowledge, practice and attitudes. A controlled study. BMS Health Serv
9 Res 2011;11:296.
10
11
12 101. Rise MB, Steinsbekk A. Does implementing a development plan for user participation in a mental
13 health hospital change patients' experience? A non-randomized controlled study. Health Expect
14 2105;18:809-825.
15
16
17 102. Rotman-Pikielny P, Rabin B, Amoyal S, Mushkat Y, Zissin R, Levy Y. Participation of family members
18 in ward rounds: attitude of medical staff, patients and relatives. Pat Ed Couns 2007;65:166-170.
19
20
21 103. Ruland CM. Decision support for patient preference-based care planning: effects on nursing care
22 and patient outcomes. J Am Med Inform Assoc 1999;6:304-12.
23
24
25 104. Ruland CM. Clinicians' use of a palm-top based system to elicit patient preferences at the bedside:
26 a feasible technique to improve patient outcomes. Proc AMIA 2000;739-43.
27
28
29 105. Sand-Jecklin K, Sherman J. Incorporating bedside report into nursing handoff: evaluation of change
30 in practice. J Nurs Care Qual 2013;28:186-194.
31
32
33 106. See MTA, Chan WCS, Huggan PJ, Tay YK, Liaw SY. Effectiveness of a patient education intervention
34 in enhancing the self-efficacy of hospitalized patients to recognize and report acute deteriorating
35 conditions. Pat Ed Coun 2014;97:122-127.
36
37
38 107. Sehgal NL, Green A, Vidyarthi AR, Blegen MA, Wachter RM. Patient whiteboards as a
39 communication tool in the hospital setting: a survey of practices and recommendations. J Hosp Med
40 2010;5:234-9.
41
42
43 108. Shulkin D, O'Keefe T, Visoni D, Robinson A, Rooke AS, Neigher W. Eliminating visiting hour
44 restrictions in hospital. J Healthcare Qual 2014;26:54-57.
45
46
47 109. Skolasky RL, Maggard AM, Li D, Riley LH, Wegener ST. Health behavior change counseling in surgery
48 for degenerative lumbar stenosis. Part II: Activation mediates the effects of health behavior change
49 counseling on rehabilitation engagement.
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 110. Stein EG, Furedy RL, Simonton MJ, Neuffer CH. Patient access to medical records on a psychiatric
4 inpatient unit *Am J Psychiatr* 1979;136:327-9.
5
6
7 111. Swenne CL, Skytt B. The ward round – patient experiences and barriers to participation. *Scand J Car*
8 *Sci* 2014;28: (8p)
9
10
11 112. Timonen L, Sihvonen M. Patient participation in bedside reporting on surgical wards. *J Clin Nurs*
12 2000;9:542-548.
13
14
15 113. Trummer UF, Mueller UO, Nowak P, Stidl T, Pelikan JM. Does physician-patients communication
16 that aims at empowering patients improve clinical outcome? A case study. *Pat Ed Couns* 2006;61:299-
17 306.
18
19
20
21 114. Turner J, Gardner B, Staples T, Chapman J. Medicines with respect (part two): Implementation and
22 evaluation of a medication management initiative in acute in-patient settings. *Ment Health Nurs*
23 2008;28:12-16.
24
25
26
27 115. Van Gaal BGI, Schoonhoven L, Mintjes JAJ, Borm GF, Hulscher MEJL, Defloor T et al. Fewer adverse
28 events as a result of the SAFE or SORRY? Programme in hospitals and nursing homes. Part i: primary
29 outcome of a cluster randomized trial. *Int J Nurs Stud* 2011;49:1040-1048.
30
31
32
33 116. Wressle E, Eeg-Olofsson A-M, Marcusson J, Henriksson C. Improved client participation in the
34 rehabilitation process using a client-centred goal formulation structure. *J Rehabil Med* 2002;34:5-11.
35
36
37 117. CA Young, Manmathan GP, Ward, JC. Perceptions of goal-setting in a neurological rehabilitation
38 unit: a qualitative study of patients, carers and staff. *J Rehabil Med* 2008;40:190-4.
39
40
41 118. L. Hollywood, D. Surgenor, M. Reicks, L. McGowan, F. Lavelle, M. Spence, M. Raats, A. McCloat, E.
42 Mooney, M. Caraher, M. Dean, Identification of behavior change technique applied in interventions to
43 improve cooking skills and food skills among adults. *Crit. Rev. Food. Sci. Nutr.* 7 (2017) 1-14.
44
45 119. L. Kahwati, M. Viswanathan, Golin C.E., H. Kane, M. Lewis, S. Jacobs S. Identifying configurations of
46 behavior change techniques in effective medication adherence interventions: a qualitative comparative
47 analysis. *System Rev.* 5 (2016) 83.
48
49
50
51 120. Soltani H, Arden MA, Duxbury AMS, Fair FJ. An analysis of behavior change technique used in a
52 sample of gestational weight management trial. *J Pregnancy* 2016;Article ID 1085916.
53
54
55
56
57
58
59
60

1
2
3 121. Goodridge D, Isinger T, Rotter T. Patient family advisors' perspectives on engagement in health-
4 care quality improvement initiatives: power and partnership. Health Exp 2017; 21:379-386.
5
6
7
8
9
10
11
12
13
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For peer review only

PRISMA 2009 Flow Diagram



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(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

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Supplementary File 1: Search Strategy - Comprehensive Medline Strategy

Database(s): Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

Search Strategy:

#	Searches	Results
1	acute care.mp. hospitals/ or exp hospitals, community/ or exp hospitals, general/ or exp hospitals, group practice/ or exp hospitals, high-volume/ or exp hospitals, low-volume/ or exp hospitals,	17713
2	private/ or exp hospitals, public/ or exp hospitals, rural/ or exp hospitals, satellite/ or exp hospitals, teaching/ or exp hospitals, urban/ or secondary care centers/ or tertiary care centers/	197791
3	hospital*.mp.	1356031
4	inpatients/ (in-patient? or inpatient?).mp. [mp=title, abstract, original title, name of substance word,	17400
5	subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	1503794
6	or/1-5	2652901
7	patient participation/	22552
8	caregivers/	29583

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Supplementary File 2. Scoping Review Data Extraction Sheet

Primary author/organization:		
Title of article:		
Source of publication (Name of journal or report):		
Year of publication:		
Reviewer initials:		
Country		
Overall Aim and Purpose of the Study		
Focus of Patient Engagement Program		
Describe the Intervention		
Duration of Program		
Theoretical Framework (Identify and describe, if present)		
Study Design (Quantitative)	Case Series	
	Cross-Sectional (Pre- and post)	
	Case-control	
	Retrospective Cohort	
	Prospective Cohort	
	RCT	
	Other	
Study Design (Qualitative)	Basic Interpretive	
	Phenomenological	
	Grounded Theory	
	Ethnographic	
	Case Study	
	Other	
Study Design (Mixed Methods)	QUAL core QUAN core Sequence	
	Instruments Used	

1	Non-Research Document	Describe type	
2			
3	Type of Hospital	Teaching	
4		Community	
5		Rehabilitation	
6		Psychiatric/Mental Health	
7		Other	
8	Type of Unit		
9	Participants	Number of participants	
10		Type of Participants	Patient Family Member Care Provider Other
11		Medical diagnoses	
12		Age range	
13		Sex (%)	
14		Inclusion criteria	
15		Exclusion criteria	
16	Results	Patient outcomes	
17		Health care provider outcomes	
18		Health system & effectiveness outcomes	
19		Funder outcomes	
20	Comments		

Supplementary File 3. Summary of Included Articles

Citation	Country	System Improvement	Description of Intervention	Study Design, Participants	Findings	BCT
30	US	Patient Safety	Patient video addressing: treatment plan, med safety, falls, surgical site identification, hand-washing and discharge planning.	Survey of 217 patients	Increased comfort in talking to providers about concerns Self-rated knowledge of patient safety improved	Shaping knowledge Antecedents (adding objects to the environment)
31	UK	PFCC: Bedside Nursing Handovers	Patient-held booklet for staff to record information on management. Aim was to facilitate communication and involve patients in rehabilitation care.	Six focus groups of therapists (n=25) Content analysis	Supportive, but questioned feasibility for both patients and staff. Ownership does not guarantee confidence needed to encourage dialogue. Differences in philosophies of care between therapists.	Shaping knowledge Antecedents (adding objects to the environment)
32	US	Patient Safety	Method to report unattended care concerns (call hospital emergency alert system). Aim to provide a practical safety net. Policies, education, audit tool signage for program.	Data on concern reports gathered over 6 months.	69 calls (3 x greater than a similar program). Key issues: plan of care; pain management; coordination of care; response to call light; other; not valid concern and dissatisfied with staff.	Antecedents (Restructuring the physical and social environment; adding objects to the environment)
33	Hospital AU	PFCC: Communication	iPad to share information with patient during ward rounds	10 senior doctors shadowed on rounds with 525	iPads were not used to share information. Patients did not believe	Antecedents (Adding objects to the environment)

				patients over 77 hours. 7 doctors interviewed and 180 patients completed survey.	iPads impacted on engagement.	
34	CAN	PFCC: Care environments	Tidal model focuses on engaging person and client-centred care in psychiatry.	46 patients and 17 staff completed short questionnaires	IPC associated with client and caregiver satisfaction (no validated instruments used)	Goals and Planning Antecedents (Restructuring the social environment)
35	UK	PFCC: Communication	Family education on delirium and psychological care via booklet – nurses promote family access to patient and encouraged interaction in ICU.	Comparative time series of 170 critically ill patients and families – 83 controls, 87 intervention	No reduction in delirium, but patients demonstrated better psychological recovery and well-being at 4, 8, and 12 weeks	Shaping knowledge Social Support
36	US	PFCC: Care environments	Create enabling environment that promoted medical patient engagement in functional recovery. Environmental and Policy Evaluation; Staff education; Ongoing training and motivation of nursing staff; FamCare. Individualized goals and mentoring.	Comparative repeated measures design; 44 dyads on intervention units and 42 dyads on control	Intervention group demonstrated better ADL and walking, less severity/duration of delirium and readmission, no significant difference in gait/balance. Families showed increased preparedness for caregiving and less anxiety but no differences in depression, strain or mutuality.	Goals and planning Feedback and monitoring Antecedents (Restructuring the physical and social environments)

37	AU	PFCC: Bedside nursing hand-over	Nurse-to-nurse bedside handover in rural hospitals.	Mixed methods, pretest, post-test approach using quasi-experimental and ethnographic elements. Ethnographic interviewing. Staff perceptions on scale and by interview. 9 inpatients and 48 nursing staff.	Patients preferred bedside hand-over (know who is caring for them, social aspects and inclusion). Staff believed patient involvement had increased.	Antecedents Restructuring the physical and social environments Scheduled consequences
38	US	Care Coordination	Educational program for nurses and social workers; cardiac patients and caregivers completed discharge planning survey and viewed video; given structured questions; given medication list and brochure on accessing community services	Before and after non-equivalent control group design with 158 dyads and 2 month follow-up in two hospitals	Patients felt more prepared to manage care, reported more continuity of information, felt they were in better health, reduced LOS when re-admitted	Shaping knowledge Antecedents (adding objects to the environment)
39	The Netherlands	Patient safety	Patient-operated mobile app MyMedication to assist with medication reconciliation. Patients create their own medication lists of the medications they actually use. Barcodes can be scanned and matched	Convenience sample of 17 elective surgery patients. AT admission, medication list in app was compared with	The use of the app shows potential as a tool to improve patient safety and reduce healthcare costs.	Antecedents (adding objects to the environment)

			with database included in the app.	list compiled by a pharmacy practitioner and discrepancies quantified.		
40	US	Care Coordination	Transition coach for medical patients. 4 pillars: assistance with medication self-management; patient-centred record owned and maintained by the patient; timely follow-up with primary or specialty care; list of "red flags" indicative of worsening condition and how to respond to them	Randomized controlled trial with 750 medical patients randomized into intervention and control groups. Primary outcome: rate of non-elective rehospitalization at 30, 90, 180 days post discharge after index hospitalization	Intervention patients had significantly lower re-admission and rates at all intervals and lower hospital costs.	Shaping knowledge Antecedents (adding objects to the environment) Feedback and monitoring Natural consequences Goals and planning
41	US	Care Coordination	Program for medical patients being discharged. 4 pillars: assistance with medication self-management; patient-centred record owned and maintained by the patient; timely follow-up with primary or specialty care; list of "red flags" indicative of worsening condition and how to respond to them	Quasi-experimental design with 158 medical patients receiving intervention and comparison with administrative data for 1,235 controls	Significant decrease in re-hospitalizations for intervention group at 30, 90 and 180 days. Participants receiving the intervention reported high levels of confidence in obtaining essential information for managing their condition, communicating with the health care team	Shaping knowledge Antecedents (adding objects to the environment) Natural consequences Goals and planning

					and understanding their medication regimen.	
42	US	PFCC: Care Planning	Integrate self-assessment and self-reporting using e-health platform (iPad) to deliver personalized care plan while hospitalized. iPad loaded with software designed to support recovery and discharge planning after cardiac surgery.	Survey of 149 patients who completed 1,418 assessments (97.6% completion)	e-Health platform, combined with mobile computing, can deliver customized care with which patients can interact. PROs have predictive value for resource use and outcomes.	Feedback and monitoring (Self-monitoring of behavior) Antecedents (Adding objects to the environment)
43	US	Care Coordination	Developed a prototype low-literacy medication education tool, customizable for each patient, using icons and photos of pills	Interviews of 166 participants two weeks and 85 participants 4 weeks after discharge	Participants who received the intervention self-reported their medication adherence more accurately and demonstrated improved knowledge about the purposes of their medications, but there was no effect on self-reported medication adherence	Antecedents (Adding objects to the environment) Regulation (Conserving mental resources)
44	US	PFCC: Communication	Provided access to iPad to input goals, preferences, concerns; view team goals, problems and schedule of events; access educational content; send messages to care team	Evaluation of usage in 239 patients and caregivers. 18/32 patients completed system usability	Most frequent use was to send messages related to health concerns, needs, preferences or questions. Use of educational content highest for medications	Goals and planning Antecedents (Restructure social environment;

				and satisfaction survey.	and test results and lowest for problems	Adding objects to the environment)
45	UK	PFCC: Care planning	Goal setting meetings with patient, relative as needed and multidisciplinary team	Case-controlled retrospective study of 105 patients comparing the number of goals set between patients admitted before and after goal-setting process introduced.	Significant increase in number of goals set per patient. Proportion of goals achieved similar to pre-intervention	Goals and planning Antecedents (Restructure social environment)
46	UK	Patient Safety	PINK is a 4 minute animated video aimed at helping patients prevent errors by encouraging to : Participate; be Informed; Notice and be alert; and Know what they can do to facilitate their recovery	Within-subjects pre- and post-screening of safety video using questionnaires with 201 patients and 95 health professionals	Post-video patients were more positive about asking doctors and nurses if they had washed their hand and notifying them about issues to do with personal hygiene. No effects on patients notifying staff about not receiving medications or in pain or unwell. Providers were more willing to support patient involvement post-video.	Shaping Knowledge Antecedents (adding objects to the environment)

1 2 3 4 5 6 7 8 9 10 11 12	47	UK	Patient Safety	Safety video (Study 1) and leaflet (Study 2) encouraging participation in safety-related behaviors	Exploratory, pre-post, within-subjects mixed methods design studies with 80 participants in each study	Increased comfort reported in engaging in some, but not all, safety-related behaviors. Patients questioned whether intervention would help reduce medical error.	Shaping knowledge Antecedents (adding objects to the environment)
13 14 15 16 17 18 19 20 21 22 23 24 25 26	48	AU	PFCC: Communication	Goal-setting interviews in rehabilitation	Exploratory, mixed methods study of 22 triads (patients, family and provider)	Provider views dominated the goal setting process. Strategies to promote goal-setting through supporting the unknown experience of injury and hospitalization: build trust; be responsive; open and honest approach.	Goals and planning
27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47	49	US	PFCC: Care planning	Family and team discussion of palliative medical condition, patient and family understanding of treatment option and disease burden, directions of medical care	Survey of 140 family caregivers post-intervention; observational data on emotional expression collected during meetings	Frequent expressions of distress from patients and families. Questions were infrequent, Patient presence significantly associated with increased discussion of goals of care, prognosis and expected symptoms at death, but decreased	Goals and planning Antecedents (Restructure the social environment)

					discussion of medical information.	
50	The Netherlands	PFCC: Communication	Passport describes, records and evaluates medical screening results to achieve treatment goals.	Qualitative (focus groups with 29 patients and 21 providers)	Purpose of passport unclear to patients. Reviews were mixed on ease of use, responsibility for completion and usefulness as an adjunct to management of diabetes. Patients expected little co-operation from internists. Barriers to fitting passport into organization of diabetes care.	Feedback and monitoring Antecedents (Adding objects to the environment)
51	UK	PFCC: Care planning	Care planning meetings including older adults	Focus groups of 20 care providers	Benefits of collaborative decision-making confirmed, although concerns about the quality of participatory practices, limited attention to group process and exclusion of those with cognitive impairment were identified	Goals and Planning
52	US	PFCC: Communication	Families invited to be present during attempted resuscitation	Survey of 70 family members	94% would participate again; 76% said grieving was facilitated by witnessing the resuscitation; 64% felt	Antecedents (Restructuring the social environment)

					their presence was beneficial to the patient	
53	US	Patient Safety	Personalized bedside screensaver of a patient safety plan that captured data from the electronic health record, including icons common to geriatric syndromes.	Phase 1: 21 end users including 6 patients participated in interviews. Phase 2: 22 end users including 6 patients participated in interviews	The Meaningful Use Program in the US requires providers to engage their patients in their health care through technology. Patients and families did not question the data on the screen saver, although some providers questioned its accuracy. Generally viewed positively, although additional work remains to be done on functionality.	Antecedents (adding objects to the environment)
54	UK	Patient Safety	“Clean Your Hands” Campaign. Study measured the effect of MRSA awareness or knowledge on patients’ willingness and comfort level in asking staff about hand-washing.	Survey of 185 patients with a response rate of 58.9% (n=109)	Access and availability of patient information about the campaign was absent. Patients were knowledgeable and aware of risks of infect while hospitalized.	Shaping knowledge Antecedents (adding objects to the environment)
55	US	PFCC: Care Environment Programs	Structured patient-centred care and engagement training program and web-based technology including ICU safety checklist, tools to develop a shared care plan and messaging platform	Prospective pre-post study of 1,030 pre and 1,075 post patient admissions	Aggregate rate of adverse events dropped by 29% during the intervention period. Patient/family satisfaction improved markedly from 71.78 to	Antecedents (Restructuring the social environment; Adding objects to the environment)

			were used by patients and care partners to view health information, participate in their care plan and communicate with care providers.		93.3 for patients. No changes were found in care plan concordance or resource utilization.	
56	US	PFCC: Communication	Electronic Bedside Communication Centre (eBCC) prototype to activate patients and bridge communication gap with professionals	Individual interviews and focus groups	The eBCC was useful and easy to use, but there were issues trying to message the team and the ability to participate in developing the plan of care. Toolkit may be confusing for older patients or those uncomfortable with technology.	Antecedents (adding objects to the environment)
57	Norway	Care Coordination	Meeting Point program consists of three seminars and four follow-up meetings with health professionals from diverse settings focused on enhancing patient participation in transitional care.	Written feedback from 85 health professionals, minutes from the plenary sessions, log reports of group facilitators and participants' written notes. Follow-up meetings were recorded and transcribed.	Program was useful in increasing providers' awareness of and competencies related to the patient's perspective in transitional care.	Shaping knowledge Identity (Framing/re-framing)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15	58	Denmark	PFCC: Care Environment Programs	Psychiatric patients with a contract can initiate a brief admission without a health professional gatekeeper	190 patients evaluated 492 admissions. The majority sought early help for mental health conditions, but also for social and everyday problems.	Primary reason was to be at peace and prevent symptom increase. Two-thirds of the patients were satisfied, although those who hoped to improved medication or wished to obtain more care were less satisfied.	Feedback and monitoring (Self-monitoring of behavior) Antecedents (Restructure the social environment)
16 17 18 19 20 21 22 23 24 25 26 27 28	59	UK	PFCC: Care Environment Programs	Developed charters, information packages, health professional visibility strategies for cardiac patients. Flexible family visiting, facilitated and supported carer involvement in care provision and improved partnership between carers and team	Pre-post intervention surveys of 43 patient and 63 carers pre- and 56 patients and 68 families post	Improved carer recognition and increase in degree they felt listened to, included, involved and supported. Noted reduction of complaints to 0 over intervention period, supporting the finding of better communication.	Antecedents (Restructure the social environment; adding objects to the environment) Social support (Practical and emotional)
29 30 31 32 33 34 35	60	US	Patient safety	Patient-held, patient-friendly medication schedule with printed reported reviewed with patients	Surveys of 100 patients	Providing patients with schedule made them partners in health care decision and provided them with knowledge about medications.	Antecedents (adding objects to the environment)
36 37 38 39 40 41 42 43 44 45 46 47	61	UK	PFCC: Communication	Trauma patients view radiographs on tablets	Pre- and post-intervention study of 2 cohorts of 50	Post-intervention patients reported significant increase in scores for perceived involvement in	Antecedent (Adding objects to the environment; restructuring

				consecutive patients	decisions made about their care and being given the right information	the social environment)
62	AU	PFCC: Communication	Care bundle for medical and surgical patients: Checklist/brochure, video and posters developed by health professionals, researchers and patients	Interviews of 11 patients who had used the care bundle	Care bundle generally well-received by patients, although they did not make use of the checklist	Shaping knowledge Antecedents (adding objects to the environment)
63	AU	PFCC: Communication	Point of service feedback using paper-based or electronic questionnaires	Cross-sectional survey of 247 patients and 221 staff	Patients preferred to give feedback during stay rather than after discharge, give feedback verbally rather than by questionnaire. Some patients feared reprisal if they gave negative feedback. Staff agreed patients should be invited to give feedback during stay. Primary reason to provide feedback was to improve services. Feedback varies with data collector.	Antecedents (adding objects to the physical environment)
64	Canada	PFCC: Care Environment Programs	Enhanced Recovery after Surgery (ERAS) is a 22 element program designed to reduce morbidity and length of hospital stay.	20 patients who had undergone colorectal surgery in past 12 months	Overarching concept was that patients wanted to take responsibility for own health from diagnosis	Shaping knowledge Natural consequences

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			Many of the elements are dependent upon patient adherence. Patient engagement framework developed. Goal was to build patient capacity within the ERAS program.	participated in patient-led focus groups and interviews. Seven patients participated in a co-design focus group to set and prioritize the research.	to recovery. Concluded no single model for patient engagement can be developed due to different cultures and contexts.	
65	US	PFCC: Communication	“Condition H” allows patients and families to initiate call to Rapid Response Team themselves.	Interviews with 21 patients and families involved with 21 Condition H events	Patients and families unanimously favorable. Most calls were related to communication issues or disagreement with treatment.	Feedback and monitoring Antecedents (Restructuring social environment; adding objects to the environment)
66	US	PFCC: Communication	Tablets used to provide health education modules (safety and discharge) and provide access to personal health records	Survey of 30 patients	Majority reported high overall satisfaction with the device, required <30 minutes of orientation. 83% completed safety module and 70% accessed their hospital record.	Antecedents (Adding objects to the environment) Shaping knowledge Feedback and monitoring
67	US	PFCC: Care Environment Programs	Wellness approach and focus on empowering medical patients/families during their stay. Live-in	Costs and health care utilizations data over 10 years	Reduced lengths of stay. 38.4% savings per hospitalization. Requires strict criteria and appropriate space.	Social support Antecedents (Restructuring the social environment)

			family or friend care partner actively involved in care.			
68	Germany	PFCC: Communication	Five one hour training sessions, including practice and feedback, for psychiatric patients on shared decision-making, including motivational and behavioral aspects	Randomized controlled trial of 61 inpatients (32 in intervention group). Control group received cognitive training.	Shared decision making training resulted in high participation preferences and increased desire to have more responsibility in treatment. Patients receiving intervention became more skeptical and were perceived as more "difficult" by psychiatrists.	Shaping knowledge Repetition and Substitution Feedback and monitoring
69	AU	Patient Safety	Patients and staff falls prevention education program ("Safe Recovery Program") comprised of DVD, workbook and 1-3 individualized sessions with physiotherapists that had been delivered to 750 patients	Qualitative exploratory study (N=10) with 9 participating in focus groups and 1 in telephone interviews, field notes	Individualized falls prevention education provides patients with capability and motivation to develop and undertake behavioral strategies to reduce falls. Educators could participate in engagement and reconciliation with staff to improve communication and outcomes.	
70	Japan	Effective Treatment	Daily voluntary training in addition to standard rehabilitation.	Clinical trial with 29 participants (21 intervention)	Voluntary training with family participation reduced length of stay and improved the rate of home discharge	Shaping knowledge Feedback and monitoring

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						Repetition and Substitution
71	US	PFCC: Communication	Evidence-based communication intervention bundles at 24, 72, 96 hours after admission to ICU. Included introduction to staff, resource folder, video, pain education, care model, resources.	Pre- and post-test design using process improvement methods. 41 pre-intervention surveys and 48 post-intervention surveys.	Family satisfaction scores for participation in decision-making and ratings of how well the team worked together showed statistically significant improvement following the intervention.	Shaping knowledge Antecedent (Restructuring social environment) Antecedents (adding objects to the environment)
72	Sweden	PFCC: Communication	Detailed written information regarding possible complications of surgery	Surveys of 182 (intervention) and 156 (control) patients undergoing surgery.	Majority of both intervention and control groups wanted more information about both common and rare complications. Intervention group significantly more satisfied with all aspects of information compared to control group both pre- and post-op.	Shaping knowledge Antecedents (adding objects to the environment)
73	US	PFCC: Care Planning	Families of ICU patients invited to participate in daily interdisciplinary rounds where team discussed plan of care.	Survey of 227 family members before and after implementation of family rounds.	Overall satisfaction scores did not differ between families who attended rounds and those who did not. Certain elements of	Antecedents (Restructuring the social environment)

					satisfaction improved, but overall satisfaction. Some families can benefit, but some feel rushed to make decisions.	
74	Sweden	PFCC: Communication	Patient-written "Tell-us" card (indicate what was most important for the patient that day) on patient perceptions of quality of care.	Quasi-experimental design using consecutive sample of 310 patients	Use of the Tell-us card resulted in significant improvements in 5 out of 17 items related to participation in decisions about medical and nursing care.	Feedback and monitoring Antecedents (Restructuring the social environment) Antecedents (adding objects to the environment)
75	Sweden	PFCC: Communication	"Tell-us" cards were used by patients to write goals for the day and indicated what mattered to them.	Interviews with 198 patients and 5 nurse managers	No improvements noted in patient participation, although culture shift noted in which staff grew to accept patients' involvement in their own care.	Feedback and monitoring Antecedents (Restructuring the social environment) Antecedents (adding objects to the environment)
76	Canada	PFCC: Bedside nursing handover	Shift hand-over conducted at medical-surgical and Ob/Gyn patients' bedsides.	Interviews with 45 patients.	Themes: creating a space for personal connection; enabled	Antecedents (Restructuring

					patients to be kept up to date; varying preferences (some patients did not see the need for bedside hand-over).	the social environment)
77	Canada	Patient Safety	Awareness campaign with 5 key safety tips for patients.	Survey of 108 hospital stakeholders (e.g. directors) and focus groups with the public.	Stakeholders were enthusiastic, although patient awareness of the campaign was low.	Shaping knowledge Antecedents (adding objects to the environment)
78	Finland	PFCC: Care Environment Programs	Activation programs for informal caregivers (booklets, invitation to participate in care); policy change (participate in an annual conference with other relatives and visitors, staff, researchers)	Interrupted time-series design with control groups of 369 caregivers conducted in 3 settings (university hospital; geriatric unit of a health centre and a nursing home)	Total participation of caregivers increased in long-term care, but not in the hospital.	Shaping knowledge Social support Antecedents (adding objects to the environment)
79	AU	PFCC: Care Environment Programs	New practice standards designed to encourage participation.	Survey of 86 community patients. Pre-post chart audits of 30 inpatient and 25 community	Modest and consistent improvements in documented carer participation were found.	Antecedents (Restructure the social environment; adding objects to the environment)

				patients (pre-), and 30 inpatients and 29 community patients (post-).		Goals and Planning
80	Germany	Patient Safety	“Patients and Families as Teachers in Patient Safety” brought interprofessional clinicians together with patients and families in 4 hour collaborative learning experience, including simulation, focused on developed patient-centred medical error disclosure communication skills.	Mixed methods with pre-post survey with qualitative and quantitative items. 55 clinicians and 18 patients and family members completed the program.	Bringing clinicians, patients and families together to discuss medical error was acceptable and feasible. Patients and families wanted to know “how the provider thinks” and more about medical error. They were interested in strategies for partnering with clinicians for safety. Patients valued experiencing clinicians’ send of accountability following medical mistakes; gained insight into the emotional impact of making an error for clinicians;	Antecedents (restructure social environment) Shaping knowledge Repetition and substitution Comparison of behavior (demonstration)
81	US	PFCC: Communication	“Go Wish” card game designed to allow seriously ill patients to consider the importance of common issues at the end of life so	Observational study of 67 patients using survey and patient rankings of goals and	25% of patients were able to complete the game. Highest value was “to be free of pain”. The card game is	Goals and Planning Antecedents (Adding objects to the environment)

			patients are prepared for discussions.	values after the game	feasible for use in inpatient settings.	
82	UK	Patient Safety	Patient Reporting and Action for a Safe Environment (PRASE) intervention consisted of: a) Patient Measure of Safety (PMOS) Questionnaire and b) a form for patients to report both safety concerns and positive experiences (patient incident reporting tool). Feedback considered in team meetings.	Clusters included 33 hospital wards within 5 hospital.	No significant effects on ward-level harm-free care and patient-level feedback on safety. Intervention uptake and retention was 100%.	Antecedents (Adding objects to the environment) Feedback and monitoring
83	UK	Effective treatment	“GetREAL” program for psychiatric patients in rehabilitation programs with predisposing, enabling and reinforcing stages	Qualitative study of 59 patients using focus groups of staff within a clustered RCT.	Intervention accepted by staff, but skills and changes to processes and structures were not sustained at the conclusion of the program. External factors such as resources limitation, lack of senior staff support, competing priorities and intensive training contributed to findings.	Antecedents (Restructuring the social environment; adding objects to the environment) Goals and planning (Commitment) Repetition and substitution
84	US	Patient Safety	Patients presented with a “Partners in Your Care” script asking them to remind health care workers to wash their hands; compliance reassessed using a modified	Interviews and direct observations of 193 patients.	Only 3% reminded at least one worker to wash their hands and 8% did not comment on hand hygiene after observing workers fail	Antecedents (adding objects to the environment) Feedback and monitoring

			script where patients were asked to thank workers for washing and/or display a sign saying "Thanks for Washing"		to wash hands. Patients are unlikely to remind workers to wash their hands.	Association (prompts and cues)
85	US	PFCC: Communication	Alert ICU patients or family members of patients who met criteria for physiological or anatomic activation of the trauma team with subsequent resuscitation were offered the option of families being present during resuscitation.	Analysis of self-administered survey of a convenience sample of family members of 140 trauma patients (70 not present during resuscitation).	Being present during resuscitation associated with reduced anxiety, reduced stress and fostered well-being,	Shaping knowledge Antecedents (restructuring the social environment)
86	Sweden	PFCC: Communication	Geriatric patients invited to team meeting which replaced rounds.	Phenomenological study with 9 nurses	Patient participation can be supported by a safe relationship in which the patient can make his or her voice heard. Participated is challenged by patients' vulnerability and by the subordinated role assigned to the patient.	Antecedents (Restructuring the social environment)
87	Canada	PFCC: Care Environment Programs	Established peer support program for psychiatric patients, strengthened patient advisory committee and creating a patient-led research team	Prospective, longitudinal approach (T1 and T2) with 25 patients. 28 providers were surveyed at T1 and T2.	Intervention had minimal impacts on internalized stigma, personal recovery, personal empowerment, service engagement, therapeutic milieu and	Social Support Antecedents (Restructuring the social environment)

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					recovery orientation of services.	
88	UK	Patient Safety	Patient Reporting and Action for a Safe Environment (PRASE) consisting of Patients Measure of Safety (PMOS) and Patient Incident Reporting Tool (PIRT) enables patients to reported detailed safety concerns and/or positive experiences. Anonymous feedback collecting using these tool present to ward staff in the form of a feedback report, followed by iterative planning cycle.	Focus groups with hospital volunteers (n=15), voluntary and patient experience staff (n=3). Semi-structured interviews with ward staff (n=5).	All stakeholders were positive about the PRASE intervention as a way to support service improvement and the benefits of including volunteers. Volunteers felt adequate training and support would be essential for retention. Staff raised concerns about infrastructure and sustainability.	Antecedents (adding objects to the environment) Feedback and monitoring
89	Spain	Effective Treatment	Individualized graduated exercise program with monitoring. Education of patients, caregivers and staff to promote mobility and functional independence	Prospective clinical trial of 17 intervention and 12 control participants.	An early supervised exercise program can reduce decline and can be maintained or improved when families are involved.	Feedback and monitoring Shaping knowledge Antecedents (adding objects to the environment)
90	UK	Patient Safety	“Partner in Your Care” program where medical-	Controlled prospective	62% of patients felt comfortable asking	Feedback and monitoring

			surgical patients asked all healthcare workers who were going to have contact with them "Did you wash your hands?"	intervention study of 39 patients. Compliance measured through soap/alcohol usage and handwashings per bed.	about handwashing. All patients asked nurses, but only 35% asked physicians.	Shaping knowledge
91	AU	PFCC: Bedside nursing handover	Nursing bedside handover	Descriptive case study of 10 patients	Patients appreciated being acknowledge as partners in care. Bedside handover was the opportunity to correct inaccuracies in information being communicated. Some patients preferred passive engagement.	Antecedents (Restructuring the social environment)
92	Norway	PFCC: Care Environment Programs	Government-legislated patient participation in care	Interviews with 15 older adults admitted to geriatric wards.	The values of older adults of community and solidarity may differ from the focus on individualism that underpins legislation. Patients often authorized family members to act and participate on their behalf due to their own declining capabilities and the hospitals' busy schedules.	Goals and Planning Antecedents (Restructuring the social environment)

93	UK	Patient Safety	Call 4 Concern is a scheme where patients and relatives can call critical care teams if they are concerned about a patient's condition.	Surveys completed by 11 patients transferring out of ICU to general wards over a six month period, 11 relatives and 4 others and 57 ICU staff members.	Patients and families felt reassured. Staff felt the system could prevent deterioration, but were concerned about inappropriate calls, increased workload and de-skilling of ward staff.	Antecedent (restructure social environment) Shaping knowledge
94	US	PFCC: Communication	Given tablets with a mobile patient portal application including pictures, names and role descriptions of team members, scheduled tests, procedures and a list of active medications.	100 intervention and 102 control-unit participants.	Significantly higher proportions of intervention named more than one physician and physician role. No difference in knowledge of nurses' names, planned tests, procedures or medications were noted between the units. No change in activation score.	Shaping knowledge Antecedents (Adding objects to the environment)
95	Finland	PFCC: Care Environment Programs	Mental health patients who are well-known to providers can refer themselves to short inpatient stays.	42 qualitative, semi-structured interviews with 28 patients with serious mental illness	Having the option to self-refer enhanced patients confidence in the services they use and in their own ability to cope with everyday life.	Antecedent (restructure the social environment) Feedback and monitoring (self-monitoring)

96	US Canada	PFCC: Care Planning	Morning interprofessional rounds used in critical care to improve team-based care, patient outcomes and involve patients and families.	Ethnographic study with 576 hours of observation, 47 shadowing experiences and 40 clinician interviews.	Rounds conducted at threshold of patient room, rather than inside of them. Involving patients was seen to “inevitably and uselessly prolong rounds”. Patient interactions were rare. Physicians felt time constraints necessitated more time spent teaching interns and less on interacting with or including patients in their own care.	Antecedents (Restructure the social environment)
97	US	PFCC: Communication	Detailed, personalized information about injuries, acute care treatment and rehabilitation progress was provided.	2x2 factorial design with 28 patients.	Intervention patients exerted greater effort in physical therapy, made greater improvement in functional independence and were more satisfied with rehab treatment.	Shaping knowledge Antecedents (Restructure the social environment; adding objects to the environment)
98	UK	Patient Safety	A 4 minute animated video entitled “PINK” aimed at helping patients prevent errors by encouraging them to : Participate; Be informed; Notice and Be alert; and Know what they	Qualitative semi-structured interviews with 36 patients	Overall favorably received. Benefits included raising awareness and facilitating patients to be involved in care. Less certainty about its	Antecedents (adding objects to the environment) Shaping Knowledge

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			can do to facilitate their recovery		ability to enhance safety. Different groups may require more tailored content in videos.	Comparison of behavior (demonstration)
99	Canada	PFCC: Care Environment Programs	“Patients as Partners” concept in programming considers medical patient full-fledged members of health care team. Uses competencies and practices for both patient and providers.	Grounded theory study with 16 semi-structured patient interviews of those who participated as “patient trainers’ co-leading inter-professional collaboration courses.	Patients described themselves as: a) continuously learning about their health; b) assessing the quality of health care received and c) adapting and compensating for optimal or non-optimal care, taking more control over decisions with their own care.	Antecedents (Restructure the social environment)
100	Norway	PFCC: Care Environment Programs	Development plan in one mental health hospital (intervention) included: establishing a patient education center, a user office, purchasing user expertise, appointing contact professionals for next of kin, improve center’s information and culture	Non-randomized controlled study using a survey of 438 professionals to compare outcomes between intervention and 2 control groups in different hospitals.	No statistically significant differences in professionals’ knowledge, practice or attitudes.	Antecedents (restructure the social and physical environments; adding objects to the environment)

101	Norway	PFCC: Care Environment Programs	Development plan in one mental hospital (intervention) included: establishing a patient education center, a user office, purchasing user expertise, appointing contact professionals for next of kin, improve center's information and culture	Survey of 1651 patients	No statistically significant effect on the patients' experience of user participation	Antecedents (Restructure the social and physical environments; adding objects to the environment)
102	Israel	PFCC: Care Planning	Ward (medical) rounds were conducted with and then without the presence of family members.	Prospective 2-phase survey study of 26 (phase 1) and 23 (phase 2) nurses and physicians, 26 and 35 patients and 32 and 40 family members	Hospitalized patients wanted family members to participate in rounds. Staff were initially reluctant, but gradually more accepting. Patients felt they had a better understanding of their medical conditions. Families felt they had more opportunity to participate in decision-making. Adjustment to the structure of rounds is necessary.	Antecedents (Restructure the social environment)
103	US	PFCC: Communication	Computer-processed information about geriatric patient preferences for self-care capability were placed in the patients' charts for staff to use in care planning.	Three group quasi-experimental design with one experimental and 2 control groups (n=151)	Information about patient preferences changes nurses' care priorities to be more consistent with patient preferences and improved patients' preference	Shaping Knowledge Goals and Planning Antecedents (adding objects to the environment)

					achievement and physical functioning	Feedback and monitoring
104	Norway	PFCC: Care Environment Programs	CHOICE is a palm-based decision support system for preference-based acute care planning that elicits patient preferences for functional performance at the bedside and to select care priorities consistent with patient preferences	Three group quasi-experimental design with one experimental and 2 control groups	Nurses' use of CHOICE changed nursing care to be more consistent with patients preferences and improved patients' preference achievement	Goals and Planning Antecedents (Restructuring the social environment; adding objects to the environment)
105	US	PFCC: Bedside nursing handover	End-of-shift report at patient bedside. Training video, hand-outs, scripts for handovers provided to nurses.	Pre- and post-survey of 232 (pre) and 178 (post) patients, 70 (pre) and 72 (post) family members and nurses. Data on Patients falls during shift change, medication errors and nurse overtime was also collected.	Statistically significant difference in patients feeling included in shift report and believing that important information was communicated between shifts. Both falls and medication errors during shift change decreased. Improved nurse perceptions of nursing accountability and patient involvement in care.	Shaping knowledge Antecedents (Restructure social environment; adding objects to the environment)
106	Singapore	Effective treatment	Patient education intervention to enhance self-efficacy of hospitalized medical patients to recognize and report symptoms of acute deteriorating conditions	Cluster RCT of 34 (intervention) and 33 (control) patients.	Level of self-efficacy in experimental group was significantly higher than control group.	Shaping knowledge Antecedents (Restructure the social environment; adding objects

						to the environment)
107	US	PFCC: Communication	Whiteboards at medical patients' bedside can be a communication tool between hospital providers and a mechanism to engage patients in care	Survey of 104 nurses, 118 house staff and 31 hospitalists	While providers valued family contact information on the whiteboard, nurses valued the importance of goals and discharge dates more than physicians. Few providers felt patients or families should be responsible for the information on the board or be involved in creating goals.	Antecedents (adding objects to the environment) Goals and Planning
108	US	PFCC: Care Environment Programs	Engagement of nurses, physicians, administrators and security in creating open visitation policy in acute care and rehabilitation hospital.	14,444 after-hours visit recorded	No increase in number of complaints from patients or visitors. Security event numbers remained the same. Unit staff received few phone calls for patient updates. Patient satisfaction scores showed positive trends but no significant change.	Antecedents (Restructure the social environment)
109	US	Effective treatment	Telephone-administered health behavior change counseling (brief motivational interviewing) of surgical patients.	Prospective clinical trial of 59 (control) and 63	Patient activation predicted engagement. The influence of counseling on rehab engagement was	Social support Regulation Antecedents: Restructuring

				(intervention) patients	mediated by patient activation.	the social environment
110	US	PFCC: Communication	Psychiatric patients given daily access to medical records with a nurse available to assist.	Survey of 88 patients and 20 staff	Patients reported feeling better informed and more involved in their treatment. Staff said they became more thoughtful about their notes.	Antecedents (Restructure the social environment)
111	Sweden	PFCC: Care Planning	Medical patient participation in ward rounds	Descriptive study of 14 inpatients who participated in interviews.	Aspects of ward rounds could be improved to promote information exchange. Information from nurses was easier to understand than information from physicians. Rounds must have an open atmosphere. Patients must be treated with empathy by staff and their right to participate acknowledged.	Antecedents (Restructure the social environment) Goals and Planning
112	Finland	PFCC: Care Planning	Afternoon reporting at surgical patients' bedsides	Survey of 118 nurses and 74 patients with observation of 76 bedside reporting sessions	Three minutes were used to give each patients' report. Patients felt this time was too short. One third of patients felt uncomfortable when other patients were present. Differences between nurse and	Antecedents (Restructure the social environment) Feedback and monitoring

					patient perceptions in terms of purpose of rounds and whether patients were to participate.	
113	Austria	PFCC: Care Environment Programs	Training program aimed at providers for empowering cardiac patients to be more effective co-producers of recuperation from surgery. 2 hour didactic session for all staff and additional 3 hour training for physicians which included role play, supervision of 3 ward rounds, admission and discharge communications.	Case study of 100 (control) and 99 (intervention)	Length of stay reduced by 1 day, incidence of post-surgical tachyarrhythmias reduced by 15%, transfer speed improved and patient rating of provider communication were improved.	Shaping knowledge Antecedents (Restructure the social environment)
114	UK	Patient Safety	"Medicines with Respect" program provided a foundation for the administration of medication and medication management strategies with client involvement. Skills training for nurses, assessment and set of clinical guidelines.	67 patient questionnaires and unspecified number of staff evaluations.	More patients were given written information; being given their medication individually instead of in a queue; improved patient compliance with medications; more carers were given sufficient information. No difference in explanations for rational for medication or patient understanding.	Antecedents (restructure social environment) Antecedents (adding objects to the environment)

115	The Netherlands	PFCC: Care Environment Programs	SAFE or SORRY program consisted of essential recommendations from guidelines on the prevention of three adverse events (pressure ulcer, falls and urinary tract infections) prevalent in older adults. Education, patient involvement and feedback occurred through a computerized registration system.	Cluster RCT of 10 wards from 4 hospital with 2201 patients and ten wards from six nursing homes with 392 patients.	Hospitalized patients receiving the intervention suffered 43% fewer adverse events than control groups. Rate ratios for the development of an adverse events were statistically significant (OR=0.57, CI 0.34-0.95) for hospital patients receiving the intervention.	Shaping knowledge Antecedents (adding objects to the environment) Feedback and monitoring
116	Sweden	PFCC: Care Planning	The Canadian Occupational Measure (COPM) is a patient-centred instrument that provides a structure for formulating treatment goals identified by the client in cooperation with the occupational therapist through an interview.	Experimental design with 155 patients in the intervention group and 55 in the control group. Structured interview with 88 patients in the intervention and 30 in the control group.	Compared to the control group, more patients in the experimental group perceived that treatment goals were identified, felt they were active participants in the goal formulation process and perceived themselves better able to manage after completed rehabilitation.	Goals and Planning Antecedents (Restructure the social environment) Antecedents (adding objects to the environment)
117	UK	PFCC: Care Planning	Goal-setting meetings for rehabilitation patients.	Qualitative study of 4 cohorts of 10 patients, carers or staff with different	All groups found goal setting beneficial, increasing motivation and providing reassurance for patients and carer.	Goals and Planning Antecedents (Restructure the social environment)

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				experiences in goal-setting	Carers found goal setting alleviated anxieties and assisted active problem-solving coping strategies. Staff believed goal setting made their practice more focused and collaborative,	Social support
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For peer review only

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	4-5
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	5
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	5
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	7
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	7
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary Table 1
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	7-8
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	8-9
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	7



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Critical appraisal of individual sources of evidence [§]	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not conducted – rationale on p. 19
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	9
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	10
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	10-11
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not done
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	11-18
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	11-18, Supplementary Table 3
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	19-20
Limitations	20	Discuss the limitations of the scoping review process.	20
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	20-21
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	21

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).



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3 From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-
4 ScR): Checklist and Explanation. Ann Intern Med. ;169:467–473. doi: 10.7326/M18-0850
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