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Strategies for Patient, Family, and Caregiver Engagement



Strategies for Patient, Family, and Caregiver Engagement

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Addendum

The literature search was updated for the manuscript related to this Technical Brief, “Patient Engagement Strategies for Adults With Chronic Conditions,” published in Systematic Reviews Journal, focusing on patient and family engagement strategies for adults with chronic conditions. We found 131 (19 from an updated search) reviews of direct patient-care strategies in adults, no additional reviews to add to the previously identified 5 reviews of health-system strategies, and no reviews of community-policy strategies. Similar to the Technical Brief, most direct patient-care reviews focused on self-management support (updated n=85) and shared decision making (updated n= 43). Overall, 49 reviews reported positive effects, 35 reported potential benefits, 37 reported unclear benefits, and 4 reported no benefits. The findings from the updated search did not change the Technical Brief’s findings.

This report is based on research conducted by the Johns Hopkins University Evidence-based Practice Center (EPC) under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. 290-2015-00006-I). The findings and conclusions in this document are those of the authors, who are responsible for its contents; the findings and conclusions do not necessarily represent the views of AHRQ. Therefore, no statement in this report should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services.

None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.

The information in this report is intended to help healthcare decision makers—patients and clinicians, health system leaders, and policymakers, among others—make well-informed decisions and thereby improve the quality of healthcare services. This report is not intended to be a substitute for the application of clinical judgment. Anyone who makes decisions concerning the provision of clinical care should consider this report in the same way as any medical reference and in conjunction with all other pertinent information, i.e., in the context of available resources and circumstances presented by individual patients.

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of healthcare in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new healthcare technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

This EPC evidence report is a Technical Brief. A Technical Brief is a rapid report, typically on an emerging medical technology, strategy or intervention. It provides an overview of key issues related to the intervention—for example, current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Although Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions, the decision to request a Technical Brief is not solely based on the availability of clinical studies. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a summary of ongoing research, and information on future research needs. In particular, through the Technical Brief, AHRQ hopes to gain insight on the appropriate conceptual framework and critical issues that will inform future research.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the healthcare system as a whole by providing important information to help improve healthcare quality.

If you have comments on this Technical Brief, they may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 5600 Fishers Lane, Rockville, MD 20857, or by email to epc@ahrq.hhs.gov.

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Key Informants

In designing the study questions, the EPC consulted a panel of Key Informants who represent subject experts and end-users of research. Key Informant input can inform key issues related to the topic of the Technical Brief. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches, and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any conflicts of interest.

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Prior to publication of the final evidence report, EPCs sought input from independent Peer Reviewers without financial conflicts of interest. However, the conclusions and synthesis of the scientific literature presented in this report does not necessarily represent the views of individual reviewers.

Peer Reviewers must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential non-financial conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential non-financial conflicts of interest identified.

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Structured Abstract

Objective: The widely applied Chronic Care Model emphasizes the need for an “informed activated patient” and a “prepared and proactive team” to improve patient outcomes. This Technical Brief applies a framework to create a map of the currently available evidence on patient and family engagement strategies that have been used to help people manage chronic conditions.

Methods: We adapted a framework for patient, family, and caregiver engagement. Key Informants provided input on the framework for categorizing different types of engagement strategies. We searched PubMed and CINAHL from January 2015 to January 2020 to identify relevant systematic reviews and to identify original research articles focused on health system and community/policy levels, which were not covered well by systematic reviews. Our gray literature search focused on reports by national organizations.

Results: Guided by our framework, we categorized patient and family engagement strategies into direct patient care, health system, and community/policy levels. The search yielded 134 systematic reviews. Of those, 126 reviews focused on the direct patient care level, 5 on the health system level, and none on the community level. Eight reviews (five with studies having comparison groups and three with studies lacking comparison groups) reported implementation outcomes. The number of studies per review ranged from 0 to 488 studies for the direct patient care level. Reviews on direct patient care level engagement mostly focused on self-management support (88) and shared decision making (34), and many used mobile health and electronic health record tools to improve engagement. The majority included studies of adults (96), while only 14 focused on children. Self-management support strategies were mostly tested as part of multicomponent interventions. Multiple technology-based modalities were used. The most frequently reported clinical outcomes were adherence to medication/self-care plans, and measures of chronic disease control (e.g., hemoglobin A1c and blood pressure control). For self-management in adults, 26 reviews reported positive effects, 18 reported potential benefits, and 19 reported unclear benefits. None reported any harms. Most reviews of shared decision making also described multicomponent interventions. Seven showed positive effects, ten showed potential benefits, eight showed unclear benefits, and one showed no benefits. Health system-level strategies most commonly involved patients and family caregivers serving on patient and community advisory councils and participating in meetings or project teams. No rigorous evaluations were reported on these strategies. One original article was identified that described patient engagement at the community level and focused on a neighborhood-clinic partnership.

Conclusions: Patient and family engagement strategies with the greatest evidence pertain to self-management support for adults with chronic conditions. Use of technology to facilitate patient and family engagement is a promising approach. Few studies examined advanced care planning or interventions for patients with multiple chronic conditions. More research is needed to address a big gap in evidence on patient and family engagement at the health system and community/policy levels.

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Evidence Summary

Key Points

- The majority of systematic reviews on patient and family engagement for the management of chronic conditions focused on direct patient care engagement strategies. For this report, direct patient care strategies are defined as strategies that directly inform the patients' own treatment decisions, health behaviors, or outcomes (e.g., self-management support, shared decision making, and communication strategies).
- The direct patient care engagement strategies most commonly included team-based care to support patient self-management, patient–provider communication using shared decision making, and mobile health and electronic health record tools to improve engagement.
- The direct patient care engagement strategies with the highest volume of evidence (i.e., several large randomized controlled trials (RCTs)) included group-based educational programs to promote chronic disease self-management by peers and other healthcare professionals; web-based and short message service interventions for cancer survivors; promising telehealth programs to promote communication, self-monitoring, and counseling; and mobile health to promote weight loss.
- Few systematic reviews or original articles focused on patient and family engagement strategies at the health system or community/policy levels. For this report, we defined a “health system level strategy” as a strategy that has an impact beyond the individual patient's care (e.g., informing changes to the services of the clinic and health care system). We defined a “community or policy strategy” as a strategy that engages patients, consumers, or citizens in policymaking or that engages communities in health care policies. We did not identify any RCTs or high-quality observational studies of health system interventions. Most existing studies at the health system level examined the impact of patient and family engagement on care processes or service delivery, policy or planning documents, and educational materials or tool development.
- Patient and family advisory councils and having patients serve on committees are the most commonly studied health system level patient and family engagement strategies.
- Health system level patient engagement strategies demonstrated some benefits, such as improvements in health care processes, development of organizational plans and policies, and education or tools.
- The single article addressing a community level patient engagement strategy described a neighborhood-clinic partnership in the Navajo Nation aimed at improving care for people living with diabetes.

Background and Purpose

Patient engagement is increasingly described as essential to improving outcomes. The objective of this Technical Brief is to apply a logical conceptual framework to create a map of the currently available evidence on patient and family engagement strategies used to help people with chronic conditions. Report findings can inform decisions of healthcare leaders as well as highlight the areas in need of more research.

Methods

We followed processes established by the Evidence-based Practice Center Program for Technical Briefs, including interviewing Key Informants. Our protocol is posted on the program's website (<https://effectivehealthcare.ahrq.gov/products/family-engagement/protocol>). The searches were conducted in January 2020. Details of the methodology can be found in the full report. Given the broad definition of patient and family engagement and the large body of evidence, we focused our search on systematic reviews, with supplemental searches for original research articles and gray literature in areas having a paucity of reviews.

Results

Building on the conceptualization of patient and family engagement by Carman et al, we categorized patient and family engagement strategies into strategies at the direct patient care, health system, and community/policy levels. The search yielded 134 systematic reviews. Of those, 126 focused on the direct patient care level, 5 on the health system level, and none on the community level. Eight reviews (five with studies having comparison groups and three with studies lacking comparison groups) reported implementation outcomes. The reviews included a large number of studies (4,111 studies for direct patient care level, without excluding duplicates). Given the low number of reviews at the health system and community/policy levels, we searched for original articles and identified three studies on engagement at the health system level and one at the community level.

Reviews on direct patient care level engagement most commonly focused on self-management support (88) and shared decision making (34), and many used mobile health and electronic health record tools to improve engagement. The majority included studies of adults (96), while 14 focused on children. Many reviews focused on single medical conditions, most commonly among people with diabetes for self-management support, followed by patients with cancer and with cancer screening needs for shared decision making. Very few reviews focused on patients with multiple chronic conditions.

Self-management support strategies were mostly tested within multicomponent interventions. These strategies included (1) education and information sharing on chronic conditions and treatment options, (2) helping patients achieve behavior change via goal setting, self-monitoring and symptom management, use of action plans, problem solving, tracking data, and feedback, (3) facilitating communication with healthcare providers and adherence to self-care plans via reminders/alerts, remote monitoring, and decision support, and (4) providing psychosocial support including healthcare navigation assistance, connection to social services and peers, counseling, and cognitive behavioral therapy. Multiple delivery methods were used, including individual and group education programs. While some strategies incorporated technology as the sole means for connecting with patients, others included in-person approaches or a mix. Technology-based approaches included devices, sensor-based technologies, gaming, videoconferencing, remote monitoring, and texting. The most frequently reported outcomes were chronic disease management measures (e.g., hemoglobin A1c and blood pressure control) followed by health-related quality of life and medication adherence. For adult self-management, 26 reviews showed positive effects, 18 showed potential benefits, and 19 showed unclear benefits. None reported any harms. More details are provided in the report on studies of children and adolescents. The two reviews that focused exclusively on studies of patients with multiple

chronic conditions showed unclear benefits, citing difficulty in operationalizing self-management for multiple chronic conditions and reduced ability to help these patients.

Most shared decision-making reviews described multicomponent interventions, including provider training and patient education, technology-enabled delivery modes (e.g., video and web-based tools), and decision support tools. Reported outcomes mainly included patient knowledge, activation, decisional conflict, and satisfaction. Few reviews reported on clinical outcomes. Seven showed positive effects, ten showed potential benefits, eight showed unclear benefits, and one showed no benefits. Within the two reviews that focused on use of patient portals, one reported provider perceptions that releasing abnormal or sensitive test results to patients could cause confusion or excess worry for patients, but there was no systematic measurement of harm.

Health system level engagement strategies most commonly included having patients and family caregivers serving on patient and family advisory councils and other committees within the health system; participating in meetings, on project teams, or forums and workshops to provide patients with skills to support engagement; or serving as instructors for healthcare professionals in training or as consultants. No rigorous evaluations reported on these strategies, and the studies were mainly limited to case reports and observational studies. Impacts of patient engagement have been reported on care processes and service delivery, priority setting, educational materials or tool development, physical space design, trainings for staff, and increasing staff awareness of patient perspectives.

No reviews and only one original article was identified that described patient engagement at the community level. The study evaluated efforts to strengthen engagement between community members and the Indian Health Service.

Limitations

This report has several limitations, including (1) use of systematic reviews rather than original studies for direct patient-care strategies due to the large body of evidence, (2) exclusion of studies on patient engagement in research, (3) focus on engagement of patients with chronic health conditions, excluding reviews on chronic disease prevention, and (4) no assessment of the risk of bias in the original studies.

Implications and Conclusions

Patient and family engagement strategies with the highest volume of evidence among adults with chronic conditions pertain to direct patient care using self-management support strategies. However, we identified inconsistent findings among reviews of self-management strategies, even within the same chronic condition. This is in part due to the heterogeneity of tested interventions, different measures, and low quality of the original studies. The evidence on engagement strategies in the pediatric population is limited by a small number of systematic reviews with few reporting on clinical outcomes. Use of technology as part of the patient and family engagement strategy is emerging as a promising approach. Few studies examined engagement strategies for advanced care planning or for patients with multiple chronic conditions. More research is needed to address a large gap in evidence on patient and family engagement at the health system and community/policy levels.

Introduction

Background

Patient and family engagement refers to patients, families, and health care providers working in active partnership across various levels to help improve healthcare outcomes.¹ While a patient may engage with their healthcare provider devising strategies to manage their own health, they may also engage at a system level with other healthcare providers and leaders in efforts to improve the care provided to all other patients. Successful patient and family engagement has potential to reduce costs, improve care processes, reduce provider burnout and improve patient outcomes.^{2,3} The widely applied and accepted Chronic Care Model emphasizes the need for having both an “informed activated patient” and a “prepared and proactive team” to improve patient outcomes.^{4,5} Patient activation refers to the level at which a patient have the knowledge, skills, willingness and ability to manage their own health.⁶ Multiple studies have demonstrated that activated patients have better health outcomes and lower utilization of emergency health care services.⁷ Conversely, reduced patient engagement in health care is associated with significant, serious, or life-threatening adverse events.⁸

In the U.S. the prevalence of chronic diseases has been increasing, necessitating a shift towards care in the ambulatory and community settings that enable long-term, sustainable strategies for preventing and managing chronic disease.⁹⁻¹¹ Interventions, such as tailored coaching that increased patient activation, have been associated with improved intermediate outcomes, including chronic disease self-management behavior and reduced health care utilization.¹² Self-management education and support interventions have also improved outcomes and function among patients with single and multiple chronic diseases.¹³⁻¹⁹

Despite the benefits of patient engagement, not all patients have the capacity to get engaged in their care, including children and patients with dementia or disability. Therefore, family and caregiver engagement strategies are needed to support vulnerable patients including children, the elderly, people at the end of life, and people with disabilities.^{20,21}

Clinicians and healthcare systems have key roles in facilitating patient and family engagement.²² Many tested interventions aim to improve clinicians’ communication skills and shared decision-making techniques,²³⁻²⁷ in part because clinicians use complicated medical jargon, limiting patients’ understanding of their care.²⁸ Communication studies show that clinicians quickly interrupt patients, allowing less opportunity for listening to concerns and building rapport.²⁹ Patients and families may not feel empowered to speak up about their concerns in health care environments, with greater risks among marginalized patients and families, including those with limited English language proficiency.^{30,31} Interventions that target patient-provider communication have improved patient satisfaction, as well as patient-centered health outcomes (e.g., symptoms of depression, anxiety, pain; management of blood pressure; and improvement in functional status).^{23-27,32,33}

Engagement at Organizational and Policy Level

Increasingly, health care systems are implementing strategies to engage patients, families, and caregivers in efforts to improve care delivery, efficiency, outcomes, and patient experience, and reduce health care costs.^{22,34,35} Part of the motivation was the Patient Protection and Affordable Care Act (2010), which tied Medicare reimbursements with scores on a patient experience survey.³⁶ A 2016 survey of over 1,450 hospitals demonstrated that most hospitals had

policies supporting patient and family engagement, including some that established patient and family advisory councils, but there was wide variation in strategy and implementation.³⁴ Patient and family engagement strategies have been integrated into advanced primary care models, including Patient Centered Medical Homes and the Comprehensive Primary Care Initiative of the Centers for Medicare & Medicaid Services.^{37,38} Diverse organizations have developed tools to promote engagement of patients and families at the organizational level, including the Agency for Healthcare Research and Quality (AHRQ), and the Institute for Patient- and Family-Centered Care, resulting in implementation guides and workshops.³⁹⁻⁴² An early review of patient and family engagement in health care design identified case studies, which demonstrated positive effects on patients' perspectives, changes to services available to patients, and improved staff attitudes toward patient engagement, but found little evidence on quality or effectiveness of care.⁴³ A more recent review identified process improvements, but few studies examined clinical outcomes.⁴⁴

The objective of this Technical Brief is to apply a logical conceptual framework to map the currently available evidence on patient and family engagement strategies that have been used to help patients, families, and caregivers manage chronic conditions. The long-term goal is to inform decision making by health systems on which engagement strategies to deploy to improve outcomes.

Conceptual Framework

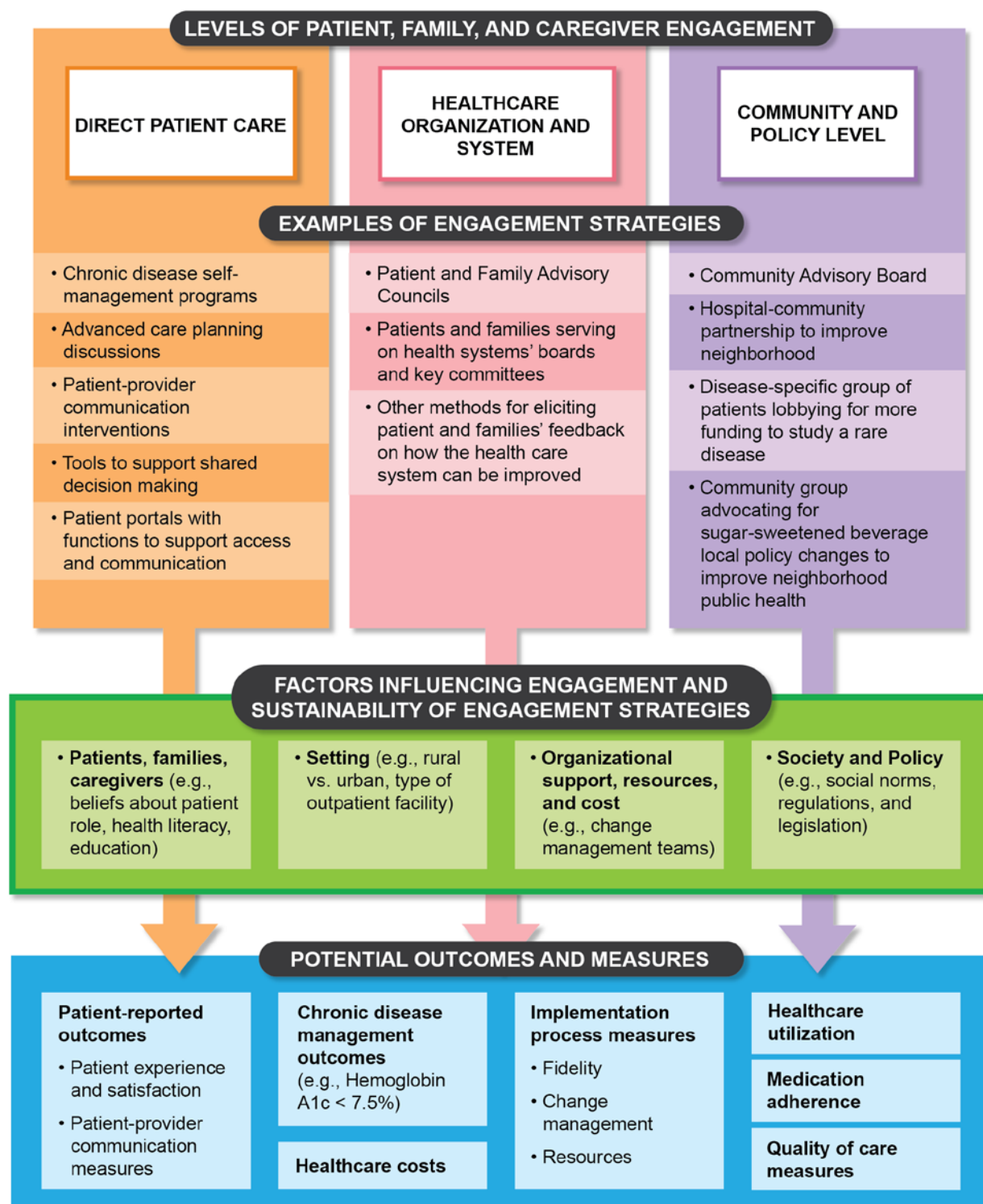
In this Technical Brief, we adapted a widely used conceptual framework on patient and family engagement interventions by Carman and colleagues, that categorizes strategies into the direct patient care level, health system or organizational level, or community/policy level (**Figure 1**).¹ We applied the definition of patient and family engagement from this framework as “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system and the community — direct care, organizational design and governance, and policymaking — to improve health and health care.”¹ We applied the adapted framework to create an evidence map displaying the evidence for patient and family engagement strategies.¹ We expanded the model related to examples of strategies and highlighting potential measures and outcomes. However, in recognition of the importance of the “continuum of engagement” (i.e., levels of how active the patient is in communication and health care decisions, and how involved the patient is in health care organization decisions) described in the original model, we focused our review on patient and family engagement that requires “involvement” and “partnership and shared leadership” (i.e., not solely consultation or one way communication) (see PICOTS, Table 1).

For the purposes of this report, we defined “direct patient care strategies” as those strategies that directly inform the patients' own treatment decisions, health behaviors, or outcomes (e.g., self-management support, shared decision making, and communication strategies). Direct patient care strategies may be delivered by the patient's primary care practice and provider, community-based organizations or the patient's health insurer through case management and population health programs. We defined a “health system level strategy” as a strategy that engages patients and families in organizational activities and/or decision making and informs the delivery of care within a health care system, beyond the individual patient's care (e.g., participation in an advisory committee or board membership). Examples include patient and family advisory councils, in which the patients and families provide feedback about how to improve the care processes and quality of care and patient experience to improve care for all patients, not just

themselves. We defined a “community or policy strategy” as a strategy that engages patients, consumers, or citizens in policymaking or that engages communities in health care policies (e.g., a hospital-neighborhood partnership to address community’s concerns, disease-specific group of patients lobbying for more funding to study a rare disease, or a community group advocating for sugar-sweetened beverage or tobacco-related local policy changes to improve neighborhood public health). We acknowledge that many of these levels overlap, as it is possible that direct care engagement strategies could also yield improvements at the system-level, and patients engaged in hospital committees could also benefit directly by improving their own care practices.

In addition, in this report we used the term “patient and family engagement” to represent engagement of the patient and family, as well as non-family caregivers, who the patient deems part of his or her care team. In addition, we intended the term “patient and family engagement” to broadly include the engagement of other consumers and citizens for the purposes of improving the quality of patient care and health outcomes for people living in the community and served by the health care system.

Figure 1. Patient, family, and caregiver engagement conceptual framework



Guiding Questions

This Technical Brief was guided by the following questions:

1. What patient engagement strategies have been studied to help patients, families, and caregivers manage their chronic conditions and improve patient health outcomes?
 - a. What are the characteristics of the patients/conditions? What is the specific role for families and caregivers? Have the subpopulations of interest been studied in the literature?
 - b. What are the characteristics of these patient and family engagement strategies?
 - c. What outcomes, including harms, have been studied?
 - d. Which elements must be implemented to have fidelity? Which elements can be adapted to reflect the local context without losing fidelity?
 - e. What resources and costs are required to implement these strategies?
 - f. What change management strategies support sustainment after implementation?
2. What gaps exist in the current research?
 - a. Which patient engagement strategies identified by experts as currently relevant have no research evidence or inadequate evidence?
 - b. For which patient engagement strategies are additional primary research studies needed to answer questions important to policy and practice of self-management?
 - c. For which patient engagement strategies are there sufficient primary research studies that a new systematic review would add to current knowledge?

Methods

We addressed Guiding Question 1 through literature review and discussion with Key Informants. We conducted a systematic literature search to identify systematic reviews on patient engagement strategies for chronic conditions. Guiding Question 2 was informed by the findings from Guiding Question 1.

Discussions With Key Informants

Key Informants were selected for their specific perspectives, including caregivers, patient representatives (e.g., from the Institute for Patient- and Family-Centered Care), health system leaders, primary care providers, nurses, payers (e.g., from Anthem, Inc.), and researchers testing patient and family engagement strategies. We solicited input on what to emphasize in the methodologic approach to the Technical Brief (e.g., strategies, methods, outcomes) and what is most important from each of their perspectives. We asked Key Informants to share their perspectives on topics that pertain to patient and family engagement and the Guiding Questions. These interviews allowed us to characterize different engagement strategies that may not appear in either the gray or published literature.

We developed interview guides, separate for each type of Key Informant, as appropriate. Box 1 lists the full set of Key Informant interview questions.

Box 1. Key Informant interview questions

From your experience or clinical practice, please identify an example of a patient, family or family engagement strategy.

We will ask you to discuss this strategy on the call and consider some of these aspects of the strategy:

- Who/what was the focus?
- What was the setting? Who was involved?
- Was it successful - why or why not?
- What contributed to it being successful or not?

Call 1: Word Cloud Brainstorm as a tool to enhance discussion: please share your words/phrases on what you think is most important to measure and know about whether a patient, family and caregiver engagement strategy is working (such as patient satisfaction, better quality of care, etc.).

Call 2: Word Cloud Brainstorm as a tool to enhance discussion: please share your words/phrases on some of the challenges that exist to implement patient, family and caregiver engagement strategies into the health system (such as costs, or lack of evidence of what works best).

We conducted interviews in small groups on the telephone. Notes were drafted for each call. Calls were recorded to assist with ensuring complete and accurate documentation.

Published Literature Search

We defined the criteria for inclusion in the review of published literature, using the PICOTS framework (Population, Intervention, Comparison, Outcomes, Timing, and Setting). Table 1 lists the eligibility criteria.

Table 1. Inclusion and exclusion criteria

PICOTS	Include	Exclude
Population	<ul style="list-style-type: none"> • Patients (children and adults) with chronic medical conditions* (e.g., DM, HTN, ESRD) and their families and caregivers • Patient representatives/caregivers serving on committees/councils aimed at improving care delivery to patients with chronic health conditions and those that over-utilize care • Subpopulations, including <ul style="list-style-type: none"> • Ethnic and racial minority • Limited language skills • Low literacy/low health literacy • Cognitive impairment 	None
Interventions	<ul style="list-style-type: none"> • Direct patient level interventions, including: <ul style="list-style-type: none"> ○ Medical home/team-based care ○ Educational resources, particularly to improve chronic disease self-management ○ Self-management programs ○ Shared decision making (e.g., palliative, end of life, or treatment decision making) • Practice, health system, and reimbursement interventions, including: <ul style="list-style-type: none"> ○ OpenNotes ○ Mobile apps ○ Patient and Family Advisory Councils • Models under alternative payment mechanisms • Community-level interventions, including: <ul style="list-style-type: none"> ○ Caregiver support ○ Peer support ○ Social support (rides to physician office, food banks) ○ Health policy initiatives ○ Community-based chronic disease management programs focused on the population's health <p>Include strategies that engage patients, caregivers, and families on Level 3 and above of the HIMSS patient engagement framework to emphasize the continuum of engagement with more patient-family involvement.^{1, 45}</p>	<ul style="list-style-type: none"> • One-time education-only or information-providing intervention (e.g., providing a handout) • Without 2-way interaction or ability for patient to ask questions (e.g., providing access to web-based educational program) • Exclude strategies Level 1 and 2 of the HIMSS patient engagement framework.⁴⁵
Comparators	<p>Any comparator (pre/post, concurrent)</p> <p>Note: For reviews addressing implementation of engagement strategies, we will not require a comparison group</p>	<p>At systematic review level - reviews without studies that had comparison groups (e.g. qualitative studies).</p> <p>At individual study level - studies without comparison group.</p>

PICOTS	Include	Exclude
Outcomes	<ul style="list-style-type: none"> Intermediate outcomes <ul style="list-style-type: none"> Clinician behavior change Clinical staff behavior change Cost/value to health system and payers Provider satisfaction Health system level changes (e.g., new population health programs) Patient outcomes <ul style="list-style-type: none"> Chronic disease morbidity Mortality Quality of life Health care utilization, including re-admissions; overuse of ER Patient reported outcomes (e.g. patient experience, satisfaction and patient activation) Implementation <ul style="list-style-type: none"> Fidelity Sustainability Barriers and facilitators Cost/resources Change management 	None
Timing	All timing <ul style="list-style-type: none"> Right after implementation strategy (within 3 months) Longer followup (3 months to 12 months) More than 12 months 	
Setting	All settings where self-management occurs (e.g., home/community/clinic/assisted living)	At systematic review level - If majority of articles in review were non-US-based studies. At individual study level - Non-US studies

*Chronic diseases are defined broadly as conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both.

DM = diabetes mellitus; ER = emergency room; ESRD = end-stage renal disease; HIMSS = Health Information and Management Systems Society; HTN = hypertension; IT = information technology

Search, Study Selection, and Data Abstraction

Our search strategies are in Appendix A. We first searched PubMed and CINAHL from January 2015 through January 2020 to identify systematic reviews. Due to the large volume of published studies, we focused on reviews published since January 2015, which would capture original articles published prior to 2015. Once we identified systematic reviews, we augmented the search by using the same search strategy (i.e., January 2015 through January 2020 using PubMed and CINAHL) to identify relevant original studies that might not have been included in the systematic reviews.

Search results were screened first at the abstract level, and then at the full-text level using the same relevant inclusion criteria. We selected original articles that focused on health system and community/policy level engagement strategies, where we had identified gaps in the search for reviews. We updated the search while the Technical Brief was posted for public comment.

Search results were screened independently by two team members, first at the abstract level, and then at the full-text level. We abstracted author, publication year, end search dates, and number and type of included studies, populations, interventions, outcomes, results, and findings from each eligible systematic review. We used the term modality to describe the interventions with regard to how they are being delivered and by whom, with categories of technology (e.g. telehealth, m health , patient portal), peer/lay support, community health worker/patient navigator, nurse/case managers, team based care, and other options (as specified). These categories were chosen based on expert input on features of commonly tested interventions. The team summarized the findings from the systematic reviews based on the assessment by the reviews' authors in their conclusions. The conclusions and degree of benefit was categorized as the following: No benefit, Unclear Benefit (mix of both positive and no or unclear benefit studies), potential (more positive studies than and no or unclear benefit studies) and positive benefit (most studies showed positive benefits in most outcomes). One reviewer categorized the conclusions and they were verified by a second reviewer.

Gray Literature

We designed the gray literature search to identify reports on health care organization/system and community strategies that might fill in gaps not covered by the published literature. We targeted the gray literature search on reports from national organizations, including the Patient Centered Outcomes Research Institute (PCORI), the Institute for Patient- and Family-Centered Care, the Institute for Healthcare Improvement, and governmental agencies such as AHRQ and the National Institute of Nursing Research, as well as information received from our Key Informants. No materials were submitted through the Supplemental Evidence and Data for Systematic Reviews (SEADS) portal.

Results

To organize the results, first, we presented the findings from the Key Informant interviews. Following the interviews, we presented the findings by Guiding Question. Within Guiding Question 1, we presented the results by level of engagement (see Figure 1). Within the direct patient care engagement level, we presented Guiding Question 1.a through 1.c by the population included in the reviews (i.e., adults, children, and then reviews that included both adults and children) followed by Guiding Question 1.d through 1.f, focused on implementation outcomes. Guiding Question 2 includes the overall evidence map to summarize the evidence and gaps.

Results of the Key Informant Interviews

We completed three 1-hour interviews with eleven Key Informants. Box 2 describes the expertise of the Key Informants.

Box 2. Key Informants' expertise

Clinicians (n=5)

- *Family Medicine*
- *Internal Medicine*
- *Director of Nursing*

Health systems perspective (n=2)

- *Patient Education, Vanderbilt University Medical Center*
- *Center for Health System Improvement, University of Tennessee Health Sciences Center*

Researchers (n=2)

- *Center for Health Equity Research, University of North Carolina School of Medicine*
- *American Institutes for Research*

Payer perspective (n=1)

- *Anthem, Inc.*

Patient/Caregiver/Advocate perspective (n=4)

- *Elder Caregiver*
- *Parent*
- *Patient*
- *Patient is Partner, LLC*
- *Institute for Patient and Family Centered Care*
- *Johns Hopkins Children's Center Pediatric Family Advisory Council*

Box 3 provides the key messages identified during the interviews. Key Informants highlighted the challenge of defining what patient and family engagement means, and how to implement and measure it in a variety of clinical and community settings. Key Informants were generally in agreement about the proposed conceptual model (see Methods) for this review. Key Informants described a broad range of strategies that could be considered patient, family, and caregiver engagement, and noted that sometimes the strategies overlapped with each other.

Box 3. Key messages from the Key Informants

Patient engagement strategies

- *Patient portals*
- *Advanced care planning*
- *Shared decision making*
- *Patient and family advisory groups*
- *Clinician training*
- *Health coaching/health education*
- *Daily hospital rounding at the bedside*

Gaps in patient engagement

- *Gaps in communication and interaction with patients or poor communication*
- *Weaknesses in the outpatient care systems*

Challenges for implementation

- *Lack of supporting evidence*
- *Lack of dedicated staff, funding, health system support*
Lack of willingness to participate – providers and patients

For direct patient care engagement, Key Informants shared their opinions about several models that are “well studied but not yet widely implemented,” including daily inpatient multidisciplinary team rounding at the patient’s bedside to review the plan of care with the patient and family, embedding of diabetes health educators into federally qualified health centers to support patients with low health literacy, and tools to facilitate shared decision making and advanced care planning.

For the level of health system engagement, Key Informants described the impact of the patient portal within the electronic health record that facilitates electronic communication with providers. Patient stakeholders valued the access to providers and quick responses they receive. Providers highlighted the challenges involved with managing the types and volume of patient requests and the possibility that patients with lower literacy or technology skills may become more marginalized. In addition, Key Informants highlighted the trend that health systems are widely implementing Patient and Family Advisory Councils to advise about a wide range of programs and initiatives. The challenge of these councils continues to be engaging diverse patients with a wide range of health care needs and including the voice of vulnerable populations. Finally, insurance companies and other payers (e.g. Medicaid and Medicare plans) are also working to incentivize patient and family engagement through value-based purchasing models and the enhancement of care coordination through their own population health programs.⁴⁶

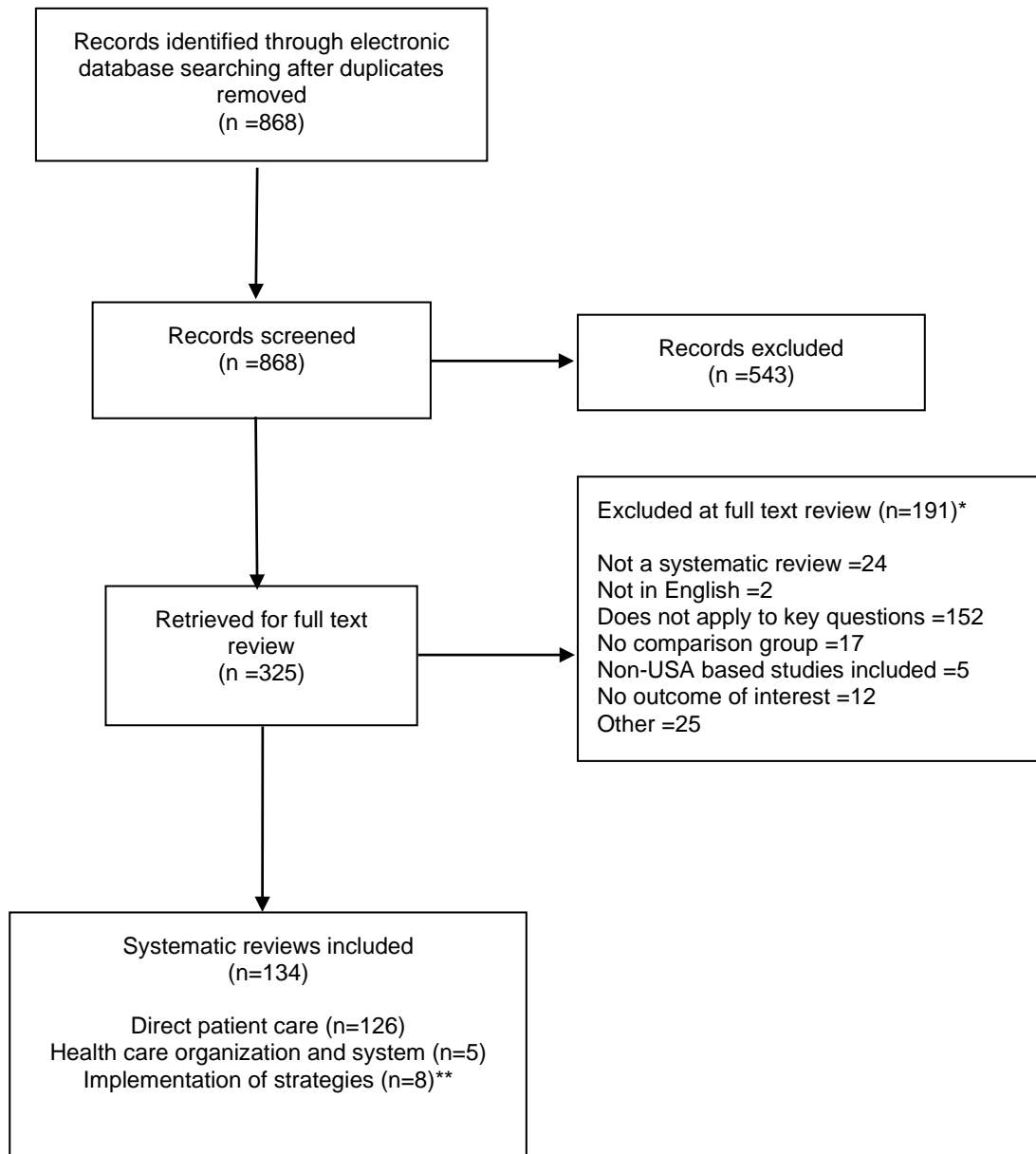
Using our “word cloud” brainstorming tool (Appendix G), Key Informants highlighted the challenges to implementing these strategies, including: a medical culture that does not prioritize patient and family input; lack of evidence for return on investment; and lack of devoted resources for implementation, evaluation, and evidence generation/dissemination. Thus, discussions with Key Informants helped to identify important aspects of strategies to examine in this review.

Results of the Published Literature Search

Figure 2 shows the search flow diagram for our main search focused on systematic reviews. The search for systematic reviews identified 868 references published between 2015 and 2020. Title and abstract review selected 325 references for full text review. One hundred thirty-four systematic reviews met the eligibility criteria. One hundred and twenty six reviews addressed direct patient care strategy, five reviews addressed health care system level strategy, and eight reviews (five with studies having comparison groups and 3 with studies lacking comparison groups) reported implementation outcomes (e.g., barriers, facilitators, resources, costs, change management). A listing of excluded studies is included in Appendix D.

Figure 3 shows the search flow diagram for original studies not included in the systematic reviews that described health system or community-level patient and family engagement strategies. A list of original studies focused on direct patient care strategy is included in Appendix F. We identified 4 original studies focused on these strategies. A listing of excluded studies is included in Appendix E.

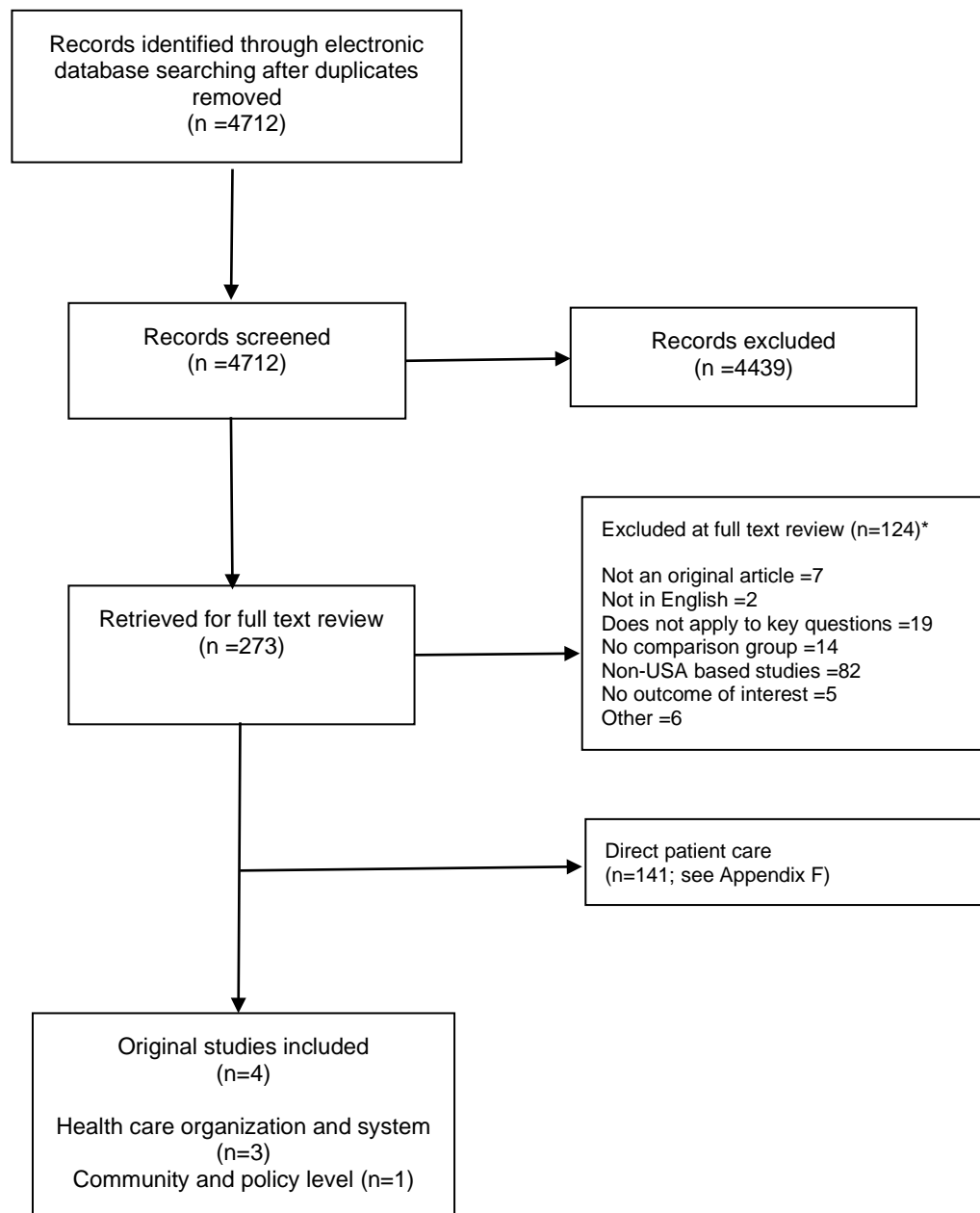
Figure 2. Search flow diagram for systematic review



* Total exceeds the number of citations in the exclusion box, because citations could be excluded for more than one reason

**Overlapping with direct patient care and health care organization and system

Figure 3. Search flow diagram for original studies



*Total exceeds the number of citations in the exclusion box, because citations could be excluded for more than one reason

Guiding Question 1: What patient engagement strategies have been studied to help patients, families, and caregivers manage their chronic conditions and improve patient health outcomes?

We identified 131 systematic reviews addressing patient engagement strategies to help patients, families and caregivers manage their chronic conditions and improve patient health outcomes. Of these, 126 focused on direct patient care strategies and five focused on health system strategies. We did not find any systematic reviews that primarily focused on community/policy strategy. The search for original research not included in the reviews identified three articles for health system strategies and one for community/policy strategy.

We presented our results for Guiding Question 1 regarding patient and family engagement strategies using the following format:

- Direct Patient Care Strategies addressing Guiding Question 1.a-1.c
 - Overview in patients with chronic conditions
 - In adults with chronic conditions
 - In children with chronic conditions
 - In adults and children with chronic conditions
 - Implementation of direct patient care strategies addressing Guiding Question 1.d.-1.f.
- Health System Strategies addressing Guiding Question 1.a-1.c
 - In patients with chronic conditions
 - Implementation of health system strategies addressing Guiding Question 1.d-1.f
- Community/Policy Strategies addressing Guiding Question 1.a-1.c
 - In patients with chronic conditions
 - Implementation of community/policy strategies addressing Guiding Question 1.d-1.f

Overview of Direct Patient Care Strategies (Guiding Question 1.a-1.c)

Definition: *Direct patient care strategy is defined as directly informing patients' own treatment decisions, health behaviors, or outcomes (e.g. self-management support, shared decision making, and communication strategies).*

We identified 126 systematic reviews evaluating direct patient care engagement strategies, with the number of included studies per review ranging from 0 to 488 studies. The range of RCTs included in these reviews were 0 to 105. We described the systematic reviews by three categories of strategies (self-management support, shared decision making/communication, and other).

Figure 4 shows the number of systematic reviews by study population (adults, children, adults and children) and across the three categories of direct patient care strategies. The majority (n=88) of reviews focused on self-management support (e.g., counseling, team-based care) and 34 reviews focused on shared decision making or enhanced patient-provider communication. Four reviews focused on other direct patient care engagement strategies. Of the 126 systematic reviews, most (n=96) studied strategies used with adults, 16 studied strategies used with children, and 14 included strategies used with both children and/or adolescents/adults (Figure 4).

Figure 4. Number of systematic reviews addressing direct patient care and family engagement strategies, by age group (n=126)

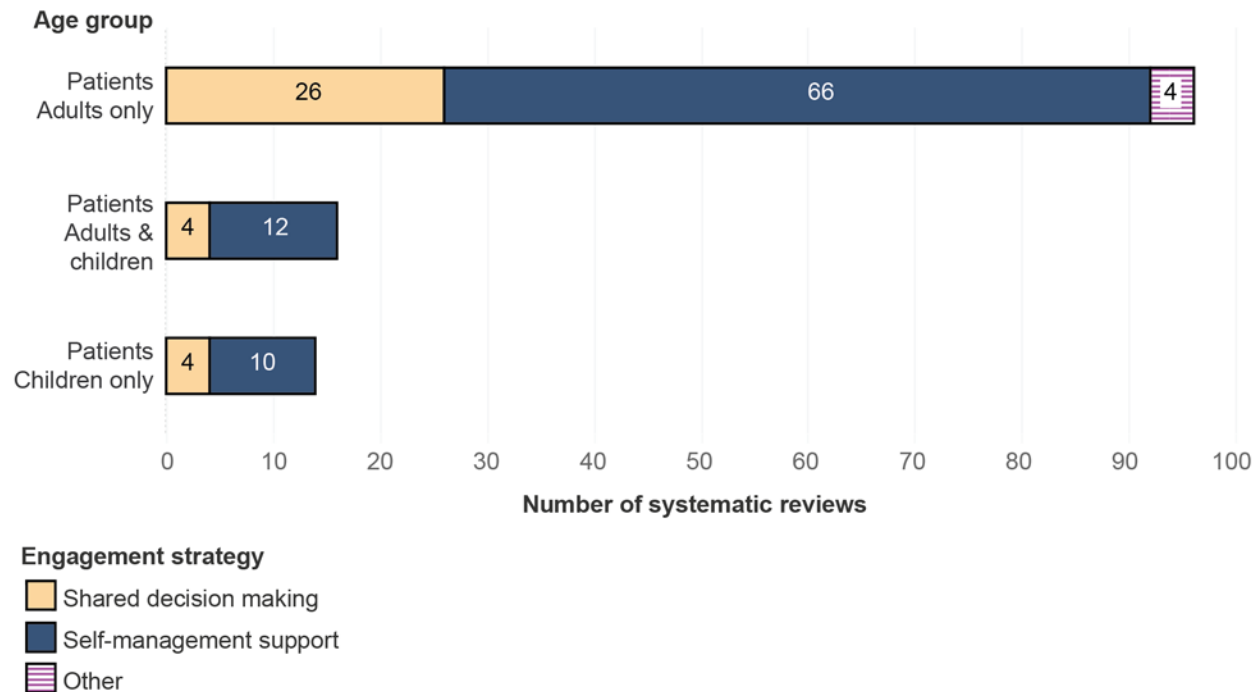


Figure 5 shows the modality (e.g., types of teams, tools or technology) for each type of direct care engagement strategy across all 126 systematic reviews. Across all age groups, the majority of reviews focused on self-management support, and among those, most reviews included nurses or case managers delivering the engagement intervention. The next most frequent modality for delivering the engagement intervention was mobile health. Among the shared decision-making interventions, most reviews focused on education and counseling, followed by engagement by nurses or case managers.

Figure 5. Intervention modality by direct patient engagement strategies (self-management support, shared decision making, or other) in systematic reviews (n=126)

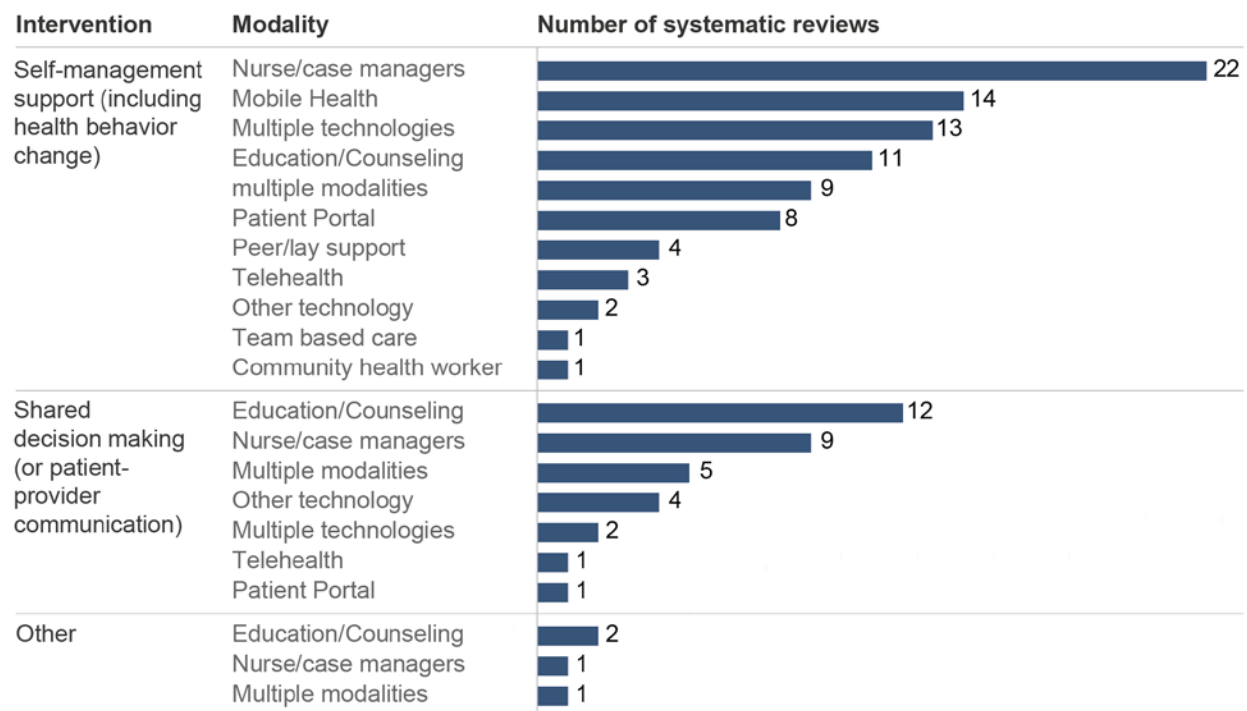
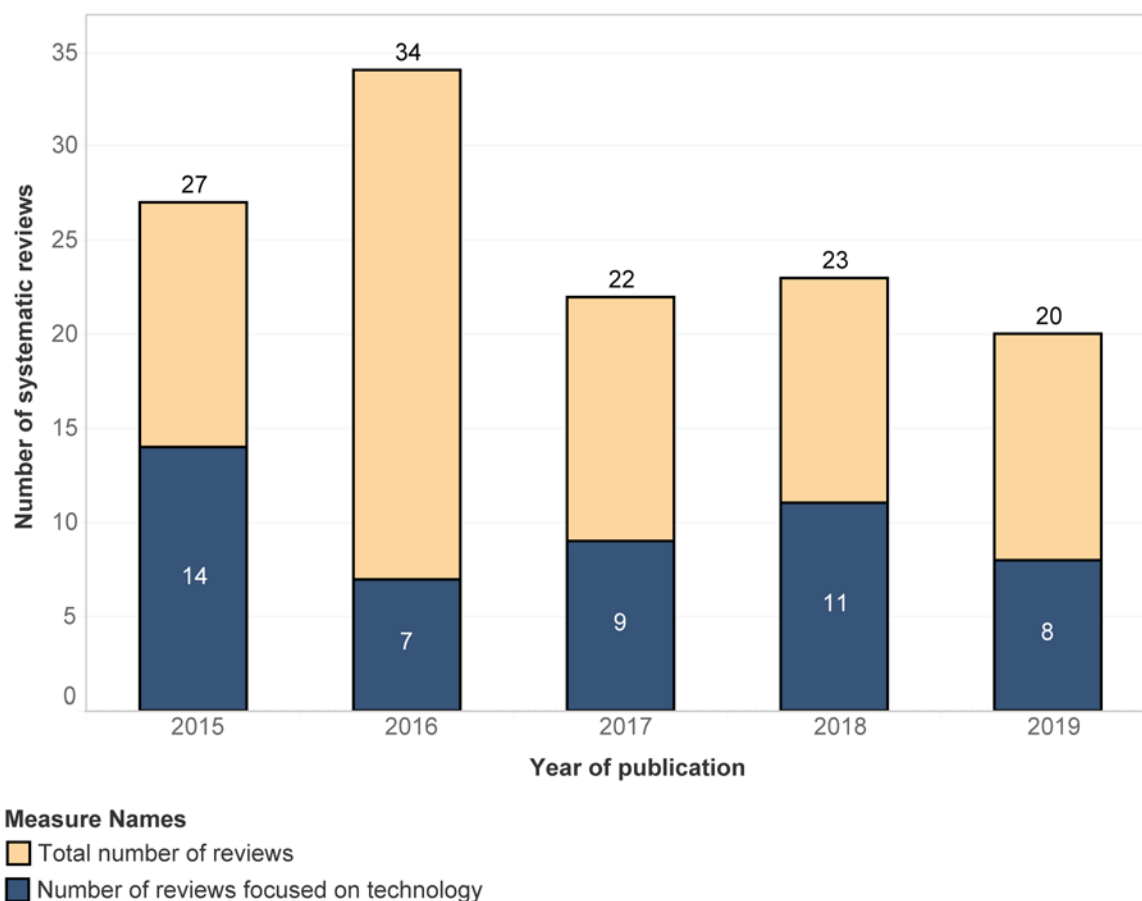


Figure 6 shows the distribution of reviews by year of publication and the number of reviews focused on technology (e.g., mobile health, electronic health record). We described the reviews that assessed the role of the patient portal, electronic health record, or mobile health within their respective sections. In 2015, 14 published reviews focused on technology, and many of these specifically assessed the role of the patient portal or secure messaging within the electronic health record on patient self-management and communication.

Figure 6. Systematic reviews on direct patient care strategies, by year and focus on technology (n=126)



Direct Patient Care Strategies – In Reviews Including Adults With Chronic Conditions (Guiding Question 1.a-1.c)

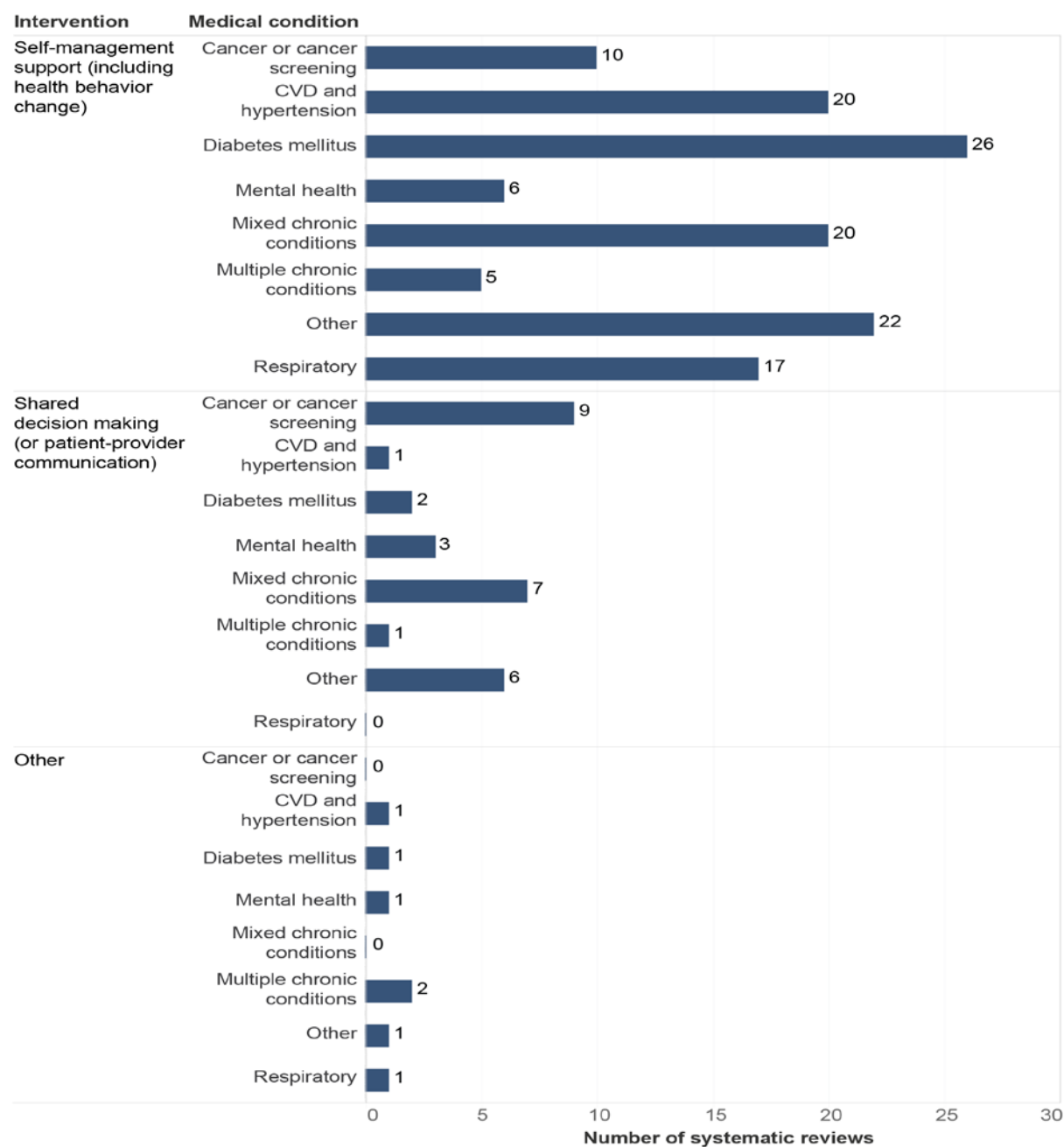
We found 96 systematic reviews that reported on direct patient care engagement strategies among adults. Of these, 66 reviews focused on self-management support (e.g., counseling, team-based care) and 26 focused on shared decision making or enhanced patient-provider communication. Four reviews focused on other direct patient care engagement strategies. (Appendix B and Figure 4).

Self-Management Support

We identified 66 systematic reviews (included studies ranged from 2 to 350; with 2 to 67 RCTs) evaluating self-management support strategies for adults.

Figure 7 shows the distribution of chronic medical conditions in these reviews. The systematic reviews focused on a range of chronic conditions including diabetes mellitus, cardiovascular disease, cancer or cancer screening, kidney disease, mental health, neurologic disease, respiratory disorders, and multiple chronic conditions. The most commonly targeted conditions were diabetes mellitus (n=26), cardiovascular disease and hypertension (n=20), respiratory disorders (n=17), and mixed chronic conditions (n=20).

Figure 7. Chronic medical conditions targeted in systematic reviews of different types of interventions for improving patient and family engagement at the direct patient care level among adults (n=96)



CVD = cardiovascular disease

Other category included = kidney disease, end of life, epilepsy, HIV, cerebral palsy, musculoskeletal, chronic pain, spina bifida, sickle cell, neurologic diseases, osteoarthritis, rheumatologic diseases

The 66 systematic reviews focused on self-management support tested a wide range of engagement strategies to help patients engage in their healthcare and support them in self-management of their chronic conditions. The strategies and interventions frequently incorporated

multiple components. These components included the following: (1) education and provision of information on health conditions and treatment options; (2) helping patients achieve behavior change via coaching and motivational interviewing, goal-setting, self-monitoring and symptom management, using action plans, problem-solving, tracking data on status and progress, and feedback provision; (3) facilitating communication with healthcare providers and adherence to treatment and self-care plans via reminders, alerts, logging, remote monitoring, and decision support; and (4) providing psychosocial support including healthcare navigation assistance, connection to social services and peers, counseling, and cognitive behavioral therapy interventions. Multiple delivery methods were used, including individual and group education programs that used face-to-face, telephonic, computer-based, and other online platforms. While some strategies incorporated technology as the sole means for connecting with patients (e.g., text messaging and digital coaching), others included in-person approaches (e.g., nurses doing home visits) or a mix of technology-based and in-person approaches (e.g., initial in-person sessions followed by e-mail and text followup). Technology-based approaches included: computer- and mobile-based devices, with or without internet connections; sensor-based technologies; gaming technology; videoconferencing; remote monitoring; and text messaging. The people involved in delivery of these strategies included physicians, nurses, occupational therapists, social workers, health educators, dietitians, psychologists, physiotherapists and other healthcare professionals, health coaches (often nurses with additional coach training), community healthcare workers, and peers (lay people with similar conditions).

Seven systematic reviews examined use of the engagement modality of the electronic health record's patient portal or secure messaging system for supporting patient self-management.⁴⁷⁻⁵³

Figure 8 shows the distribution of the outcomes addressed in the systematic reviews of self-management among adults, which included the following outcomes: chronic disease clinical outcomes (e.g., hemoglobin A1c, blood pressure), health care utilization (e.g., re-admissions and emergency department use), adherence to medication or self-management tasks, patient satisfaction or experience, quality of life, decisional support outcome, and mortality. The most frequently reported outcomes were adherence to medication or self-management tasks (77%), chronic disease clinical outcomes (66%), quality of life (44%), and health care utilization (23%).

Figure 8. Patient and family engagement outcomes assessed for different types of interventions at the direct patient care level, among adults, as reported in systematic reviews (n=96)

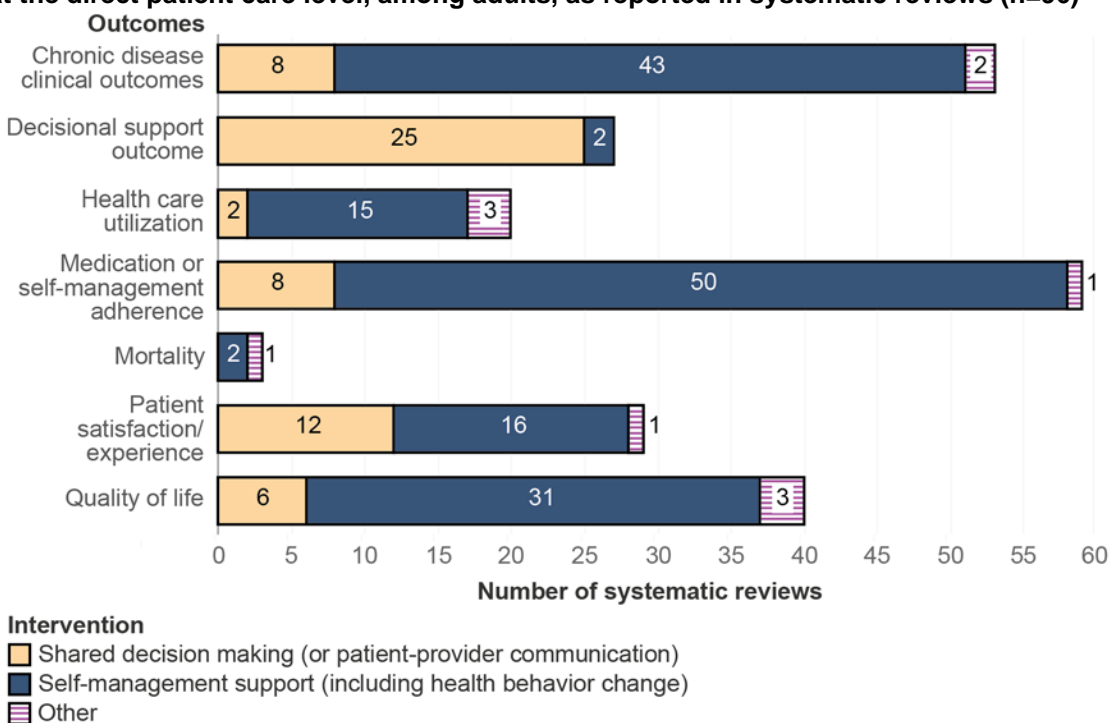


Figure 9 shows the findings by strategy. While 40 percent of the systematic reviews showed definite positive effects, 28 percent showed potential benefits, and 28 percent could not make any conclusions about benefit. No reviews reported any harm.

Table 2 reports the findings by strategy and health condition. Reviews of self-management support for diabetes and cardiovascular disease, and reviews of shared decision-making for cancer and cancer screening commonly reported benefits. We found two reviews that focused on transitional care for adults with chronic conditions and both reported benefits.

Thirteen systematic reviews focused on self-management support for diabetes mellitus and reported on diabetes outcomes. Of those, four showed benefits for measures of glycemic control and diabetes knowledge,⁵⁴⁻⁵⁷ and one showed cost benefits for educational support interventions.⁵⁸ Benefits were unclear for the impact on quality of life and utilization. Six systematic reviews focused on self-management support interventions among cancer patients, and three showed potential and clear benefits.⁵⁹⁻⁶¹ One of those was a systematic review and meta-analysis of 34 RCTs of web-based self-management support interventions for cancer survivors. The meta-analysis showed positive effects on fatigue, depression, anxiety, and overall quality of life. The communicative functions of the web-based interventions had showed benefits, particularly access to other peers.⁵⁹ Out of three systematic reviews focused on self-management support for cardiovascular disease, one showed no benefits⁶² and two showed mixed findings.^{63,64} Self-management interventions showed promising benefits for improving overall risk factor control among patients with stroke.⁶⁵ For adults with asthma, one review showed low to moderate quality evidence for improvement of asthma-specific quality of life, asthma severity, and lung function tests with chronic disease management programs of at least 3

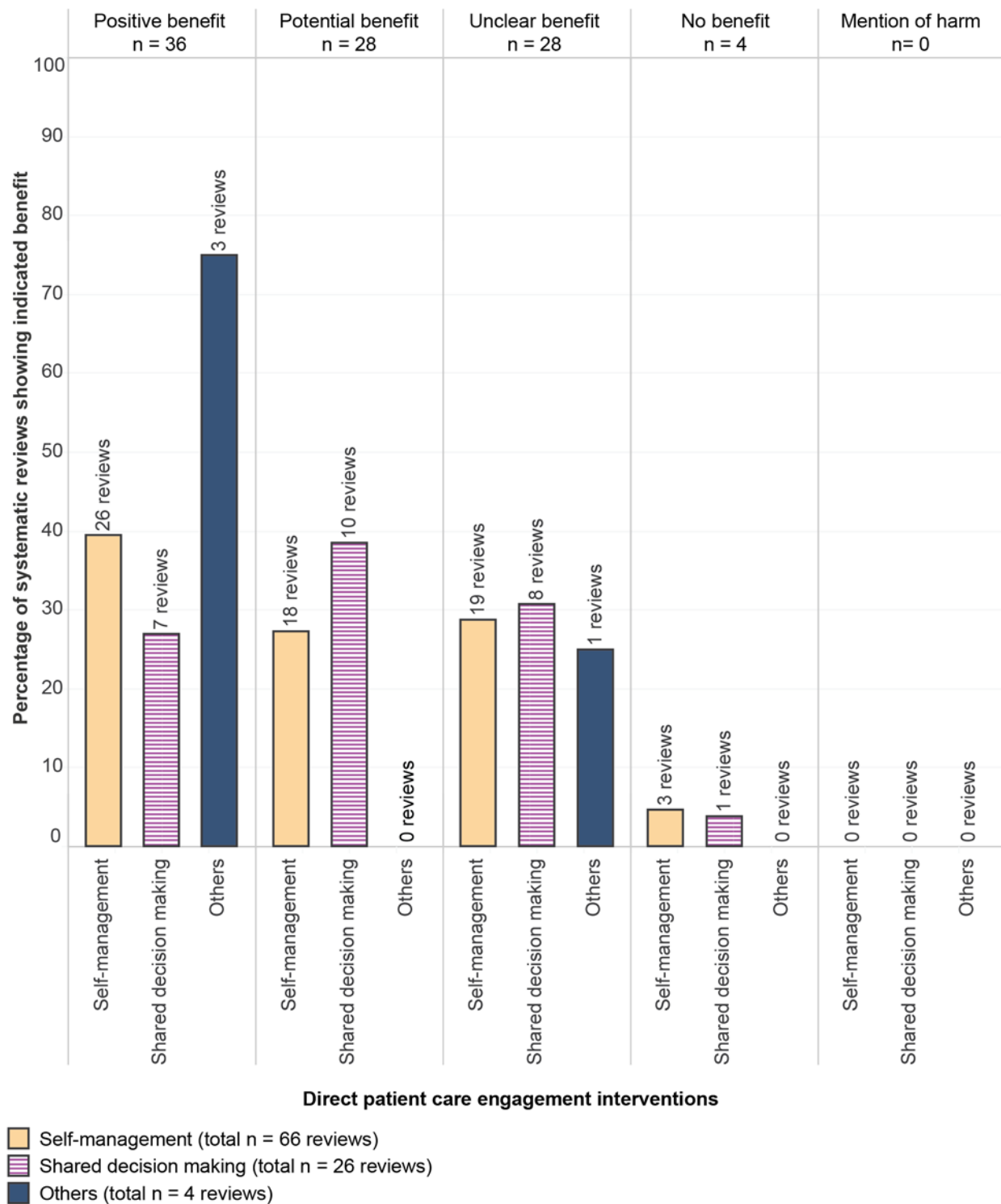
months duration with self-management support as a component along with healthcare professional support, care coordination, and/or system level components.⁶⁶

Two large systematic reviews showed benefits to low-income, underserved, and racial and ethnic minority patients from interventions delivered by community health workers, specifically in the area of diabetes control, hypertension, and cancer screening behaviors.^{54,67} Two systematic reviews that only included studies of patients with multiple chronic conditions showed unclear benefits, citing difficulty in operationalizing self-management for multiple chronic conditions and a reduced ability to help these patients.^{68,69}

One systematic review reported findings of a pooled analysis including 2,742 patients in which phone text messaging interventions doubled the odds of medication adherence. However, the authors cautioned that more research is needed given short study durations and use of self-reported medication adherence measures.⁷⁰

Two reviews focused on studies involving caregivers. One study, which looked at a broad range of patient- and family-centered self-care interventions for patients with several types of chronic conditions,⁷¹ included nine RCTs and showed positive impact on reduced rehospitalizations with varied impact on health-related quality of life (HRQOL). The other systematic review focused on studies of self-management support interventions for patients with chronic obstructive pulmonary disease (COPD) and chronic heart failure. The review did not find evidence of additional improvement in patient HRQOL among those studies that involved caregivers compared with the rest of the studies.⁷² Among the eight systematic reviews focused on patient portals as engagement modality, one study focused on a clinical outcome (hemoglobin A1c⁵³) and the other studies focused on patient experience, patient knowledge, and patient empowerment. The systematic review by Kuo and colleagues included 11 studies that addressed the role of the patient portal to support diabetes self-management and found that 7 of the 11 studies showed improvement in patients' hemoglobin A1c with the use of secure messaging.⁵³





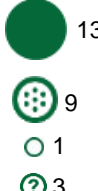


















Figure 9. Percentage of systematic reviews reporting benefits of different types of direct patient care interventions for improving patient and family engagement, among adults, as reported in systematic reviews (n=96)*













*Each percentage is calculated based on the total number of reviews on a given type of intervention

Unclear benefit = In five reviews of self-management, the review question was not about evaluating outcomes

Table 2. Number of systematic reviews reporting benefits among adults, stratified by interventions and conditions

Conditions	Self-Management Support (n=66)	Shared Decision Making (n=26)	Transitional Care (or transition support) (n=2)	Other (Advanced care and health literacy) (n=2)
Overall*				
Diabetes mellitus			None	
CVD and hypertension			None	
Respiratory		None	None	
Cancer and cancer screening			None	None
Mental health			None	
Other			None	
Multiple chronic conditions				None

Conditions	Self-Management Support (n=66)	Shared Decision Making (n=26)	Transitional Care (or transition support) (n=2)	Other (Advanced care and health literacy) (n=2)
Mixed chronic conditions	 9  3  8	 2  2  3	None	None

-  Positive benefits
-  Potential benefit
-  No benefit
-  Unclear

Circle size corresponds to number of reviews reporting the type of benefit for a specific health condition.

CVD = cardiovascular disease

* Total exceeds the number for overall because reviews could be included for more than one specific condition as reported in the systematic review.

Shared Decision Making or Patient-Provider Communication

We identified 26 systematic reviews evaluating shared decision making or patient-provider communication engagement strategies for adults with chronic disease (Appendix B). The systematic reviews that evaluated shared decision making or patient-provider communication included between 4 and 120 studies each (with a range of 1 to 105 RCTs). The shared decision-making reviews focused on a range of chronic conditions, including diabetes mellitus, cardiovascular disease, cancer or cancer screening, kidney disease, mental health, neurologic, respiratory, and multiple chronic conditions.

The systematic reviews most often focused on cancer/cancer screening (n=9), mixed chronic conditions (n=7), mental health conditions (n=3), and diabetes (n=2). For example, the systematic review by Stovell and colleagues identified 11 RCTs that reported on shared decision-making outcomes in patients with psychosis (Figure 7).⁷³

Most shared decision-making interventions involved multiple components, including provider trainings and patient education tools, which included technology-enabled delivery modes (e.g., video, web-based tools) and decision supports. The largest systematic review (n=105 studies), a Cochrane review by Stacey and colleagues, broadly assessed decision aids for people facing health treatment or screening decisions.⁷⁴ This review also evaluated whether studies had considered the health literacy of their patient populations, such as adapting tools for lower literacy patients.⁷⁴ Most interventions included guidance and coaching for patients and training for physicians, as well as education for patients.⁷⁴ Two systematic reviews specifically evaluated shared decision-making engagement strategies for advanced care planning.^{75,76} The systematic review by Vermunt and colleagues focused on collaborative goal setting for older patients with chronic diseases⁷⁵ and reported on five interventions included in eight studies, most commonly reporting on tools and team-based discussions. Two systematic reviews examined the role of the electronic health record's patient portal or secure messaging system as an engagement strategy to enhance patient-provider communication.^{52,77} One systematic review focused on patient engagement using an inpatient portal for communication,⁵² and the other review focused on the outpatient clinical setting.⁷⁷

Figure 8 shows the frequency of outcomes reported in the studies involving the engagement strategy. Most of these systematic reviews focused on patient-reported outcomes including patient activation, patient knowledge, patient's decisional conflict, and satisfaction with the decision-making process. Few reviews reported on clinical outcomes. The systematic review by Kashaf and colleagues reported on shared decision making among patients with type 2 diabetes and showed a lack of association with shared decision making and outcomes of glycemic control, patient satisfaction, quality of life, medication adherence, or trust in physician.⁷⁸ The systematic review by Vermunt and colleagues included eight studies and showed statistically significant improvements in process measures, including application of goal setting for older patients with chronic diseases in the four intervention studies.

Figure 9 shows the findings on benefits of shared decision-making interventions, as reported by the systematic reviews. Overall, systematic reviews showed an unclear or potential benefit of the interventions on the patient-reported and documentation outcomes, with few studies reporting clinical benefits. Among the two studies focusing on the patient portal to enhance patient-provider communication, the outcomes focused on patient experience, patient knowledge, and patient-provider communication. One study noted, but did not systematically measure, harms, including provider perception that releasing abnormal or sensitive test results to patients could cause confusion or excess worry for patients.

Other Interventions

We identified four systematic reviews that focused on engagement around care transitions,^{79,80} advanced care planning,⁸¹ and specific educational programming for patients undergoing peritoneal dialysis.⁸²

The two reviews on transitional care support strategies among adults with chronic disease included a range of engagement interventions with patient education and support (e.g., motivational interview/individualized face-to-face coaching, follow up phone calls, and home visits), as well as care coordination components (e.g., coordination of hospital and primary care, medication management).^{79,80} Both reviews showed positive impact on outcomes. The largest, a systematic review and meta-analysis that included 92 studies from Europe, Asia, North America, and Oceania,⁷⁹ focused on patients 65 years of age and older with at least one chronic disease. The review showed that, compared with usual care, interventions to help support these patients after hospitalization reduced mortality and healthcare utilization (number needed to treat to reduce mortality at 3 months was 50; to reduce readmissions at 3 months was 7), without significant differences in quality of life.

A Cochrane review by Coulter and colleagues examined 19 studies (16 RCTs) focused on advanced care planning for adults with long-term or chronic health conditions. The engagement interventions included a variety of tools to facilitate goal setting and action planning, including patient information packets (e.g. digital versatile discs or books), structured consultations with health coaches, and individual and group visits. Fifteen of the 19 studies showed a positive effect in at least one outcome, such as physical health, psychological health and health behaviors, and three studies reported on hospital readmissions, medication usage and cost-effectiveness.⁸¹

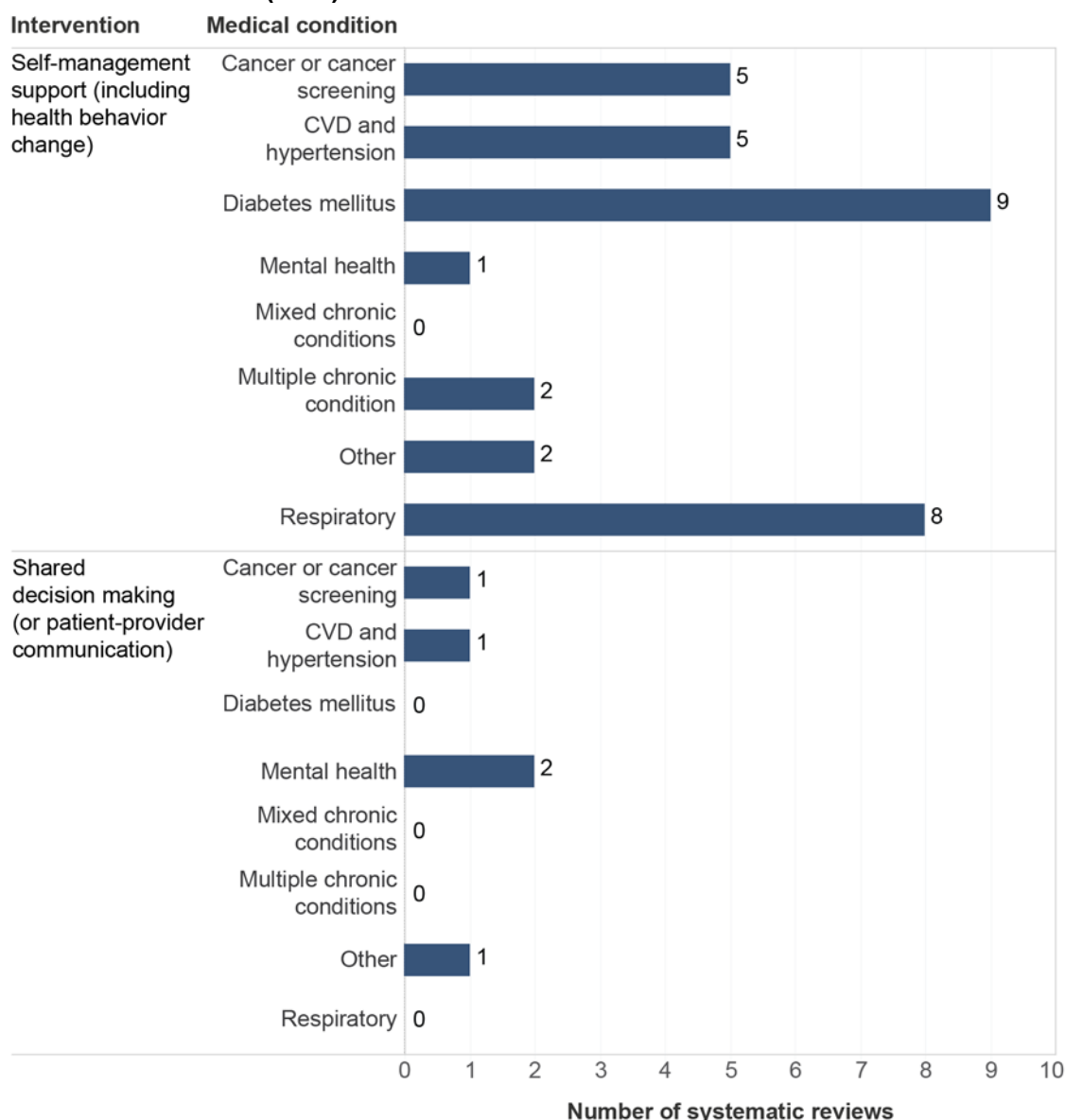
Among the systematic reviews of direct patient care interventions in adults, 8 reviews included patients with multiple chronic conditions (5 with self-management support interventions, one with shared decision-making intervention and 2 with transitional care interventions). Five of the 8 were deemed to have positive benefit (see Table 2).

Direct Patient Care Strategies – In Reviews Including Children With Chronic Conditions (Guiding Question 1.a-1.c)

We identified 14 systematic reviews evaluating direct patient care engagement strategies for children and adolescents with chronic disease (Figure 4). One review focused on adolescents alone (12 to 18 years of age);⁸³ six on children and adolescents (0 to 18 years of age);⁸⁴⁻⁸⁹ one on adolescents and young adults (11 to 25 years of age);⁹⁰ and, six on children, adolescents, and young adults (0 to 28 years of age).⁹¹⁻⁹⁶ The 14 reviews included studies with a range of 0 to 93 studies (included RCTs ranged from 0 to 93).

Figure 10 shows the chronic health conditions reported in the 14 systematic reviews that reported on direct patient care engagement strategies in children and adolescents. The most frequently examined conditions were diabetes mellitus (9 reviews)^{83,84,86,91-96} and asthma (8 reviews),^{84,86,91-96} followed by cystic fibrosis (5 reviews),^{83,84,91-93} cancer (5 reviews),^{84,86,93-95} and blood disorders (4 reviews).^{84,86,89,93} Five systematic reviews included studies with family caregivers (i.e., parents/guardians),^{84,86,87,89,96} including one in which caregivers were the primary population of interest.⁸⁴ No systematic review in this group specifically intended to examine a vulnerable patient population. Of the 14 systematic reviews, three examined strategies primarily used in the home,^{84,91,94} two focused on strategies primarily used in the clinic setting,^{87,89} three reported on strategies primarily used in the inpatient setting,^{83,86,90} and four focused on strategies used in multiple settings.^{92,93,95,96} Three reviews included school and/or camp settings.^{92,93,96}

Figure 10. Chronic medical conditions targeted in systematic reviews of different types of interventions for improving patient and family engagement at the direct patient care level, among children and adolescents (n=14)



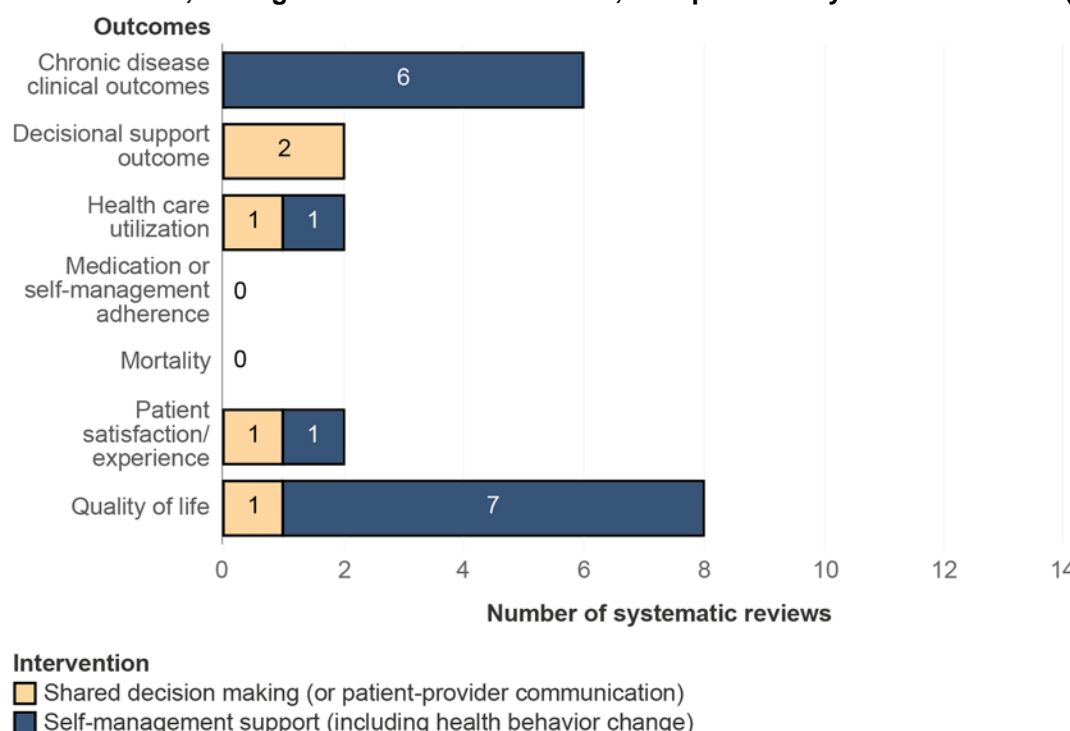
CVD = cardiovascular disease

In the 14 systematic reviews of direct patient care engagement strategies in children and adolescents, the only engagement strategies evaluated were self-management support (10 reviews) and shared decision making (4 reviews) (Figure 5). Three reviews evaluated self-management engagement strategies in the context of transitions of care, including team-based care, education/coaching sessions or counseling, and peer/lay-support.^{83,86,90} Three reviews on direct patient care engagement strategies focused on technology (i.e., mobile applications, web-based care, and/or video games) and four reviews described studies where at least one component of education/coaching sessions was delivered in combination with technology. For example, a systematic review by Charlier and colleagues reviewed the effectiveness of health-related video games on the self-management skills of children, adolescents, and young adults.⁹⁵

Among the four systematic reviews in children and adolescents that evaluated shared decision-making strategies, two reported on interventions with education/coaching sessions and decision aids.^{87,89} The systematic review by Cheng and colleagues examined the use of shared decision making in children and adolescents with mental health disorders. Most of the RCTs included in the review showed that parents using shared decision making with providers had lower decisional conflict, and more engagement with treatment, and more of the parents' priorities were addressed.⁸⁷ Wyatt and colleagues also demonstrated a significant reduction in decisional conflict in a meta-analysis of nine studies that contained a heterogeneous population of children with and without chronic disease.⁸⁹

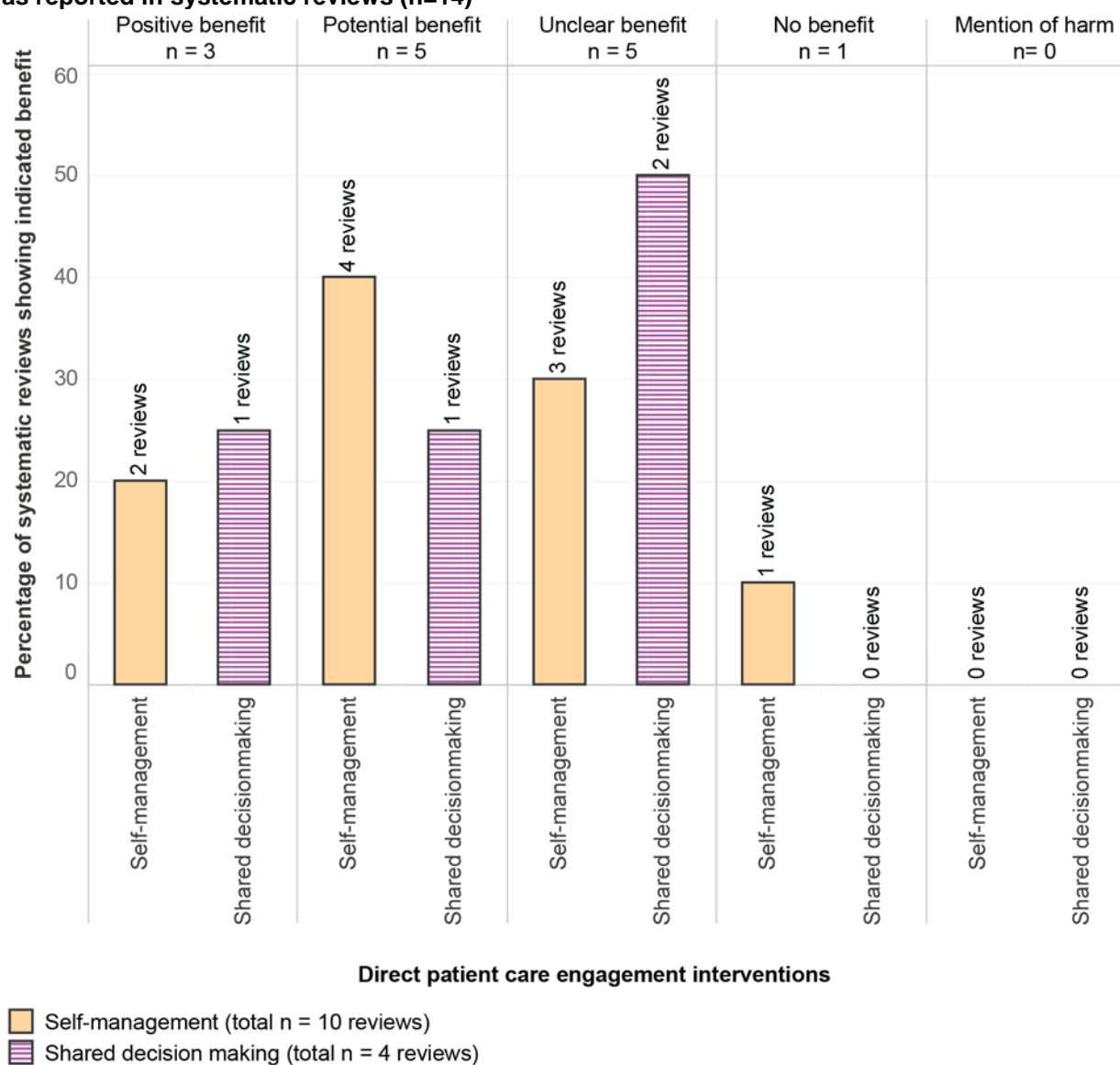
The 14 systematic reviews of direct patient care engagement strategies in children and adolescents reported on the following engagement outcomes: quality of life (8 reviews), medication or self-management adherence measures (7 reviews), and chronic disease clinical outcomes (6 reviews) (Figure 11). Two reviews reported healthcare utilization, decisional support, and patient experience/satisfaction measures. In the largest review for this population (n=93 studies), Knafl and colleagues described the nature of family engagement interventions for children with chronic disease.⁸⁴ This review reported that engagement strategies promoting family function (i.e., problem solving, communication skills, cohesion) improved measures of child well-being, condition control, and adherence measures. In another example, the systematic review by Hamline and colleagues evaluated hospital to home interventions in 31 studies of children with chronic disease.⁸⁶ In this review, family engagement interventions, along with care coordination, were associated with a more than 50 percent reduction in hospital readmissions and a 25 percent reduction in emergency room visits following inpatient discharge. The review found that parent education by the engagement strategy of “teach backs” and the use of contingency plans were the most consistently effective in reducing post-discharge utilization.

Figure 11. Patient and family engagement outcomes assessed for different types of direct patient care interventions, among children and adolescents, as reported in systematic reviews (n=14)



Overall, the 14 systematic reviews of direct patient care engagement strategies in children and adolescents showed positive effects in 3 reviews or potential benefit in 5 reviews. Three reviews showed unclear benefit,^{83,94,96} one described no benefit,⁹¹ and two did not report any findings.^{85,88} No reviews reported harms associated with patient and family engagement strategies (Figure 12).

Figure 12. Percentage of systematic reviews reporting benefits of different types of direct patient care interventions for improving patient and family engagement, among children and adolescents, as reported in systematic reviews (n=14)*



*Each percentage is calculated based on the total number of reviews on a given type of intervention

Unclear benefit = In one review of shared decision making, the review question was not about evaluating outcomes

Table 3 depicts the findings from reviews for specific chronic health condition by type of engagement strategy in children and adolescents. Reviews that focused on studies of patients with diabetes, cardiovascular disease, and respiratory diseases commonly reported benefits with self-management support interventions. Shared decision making interventions were reported to be beneficial among patients with mental health conditions.

Table 3. Number of systematic reviews reporting benefits among children and adolescents, stratified by interventions and conditions

Conditions	Self-Management Support (n=10)	Shared Decision Making (n=4)	Transitional Care (or transition support) (n=0)	Other (Advanced care and health literacy) (n=0)
Overall*	● 2 ● 4 ○ 1 ? 3	● 1 ● 1 ? 2	None	None
Diabetes mellitus	● 2 ● 3 ○ 1 ? 3	None	None	None
CVD and hypertension	● 2 ● 2 ○ 1	? 1	None	None
Respiratory	● 2 ● 3 ○ 1 ? 2	None	None	None
Cancer and cancer screening	● 1 ● 3 ? 1	? 1	None	None
Mental health	● 1	● 1 ● 1	None	None
Other	● 1 ? 1	● 1	None	None
Multiple chronic conditions	● 1 ○ 1	None	None	None
Mixed chronic conditions	None	None	None	None

● Positive benefits

● Potential benefit

○ No benefit

? Unclear

Circle size corresponds to number of reviews reporting the type of benefit for a specific health condition.

CVD = cardiovascular disease

*Total exceeds the number for overall because reviews could be included for more than one specific condition as reported in the systematic review.

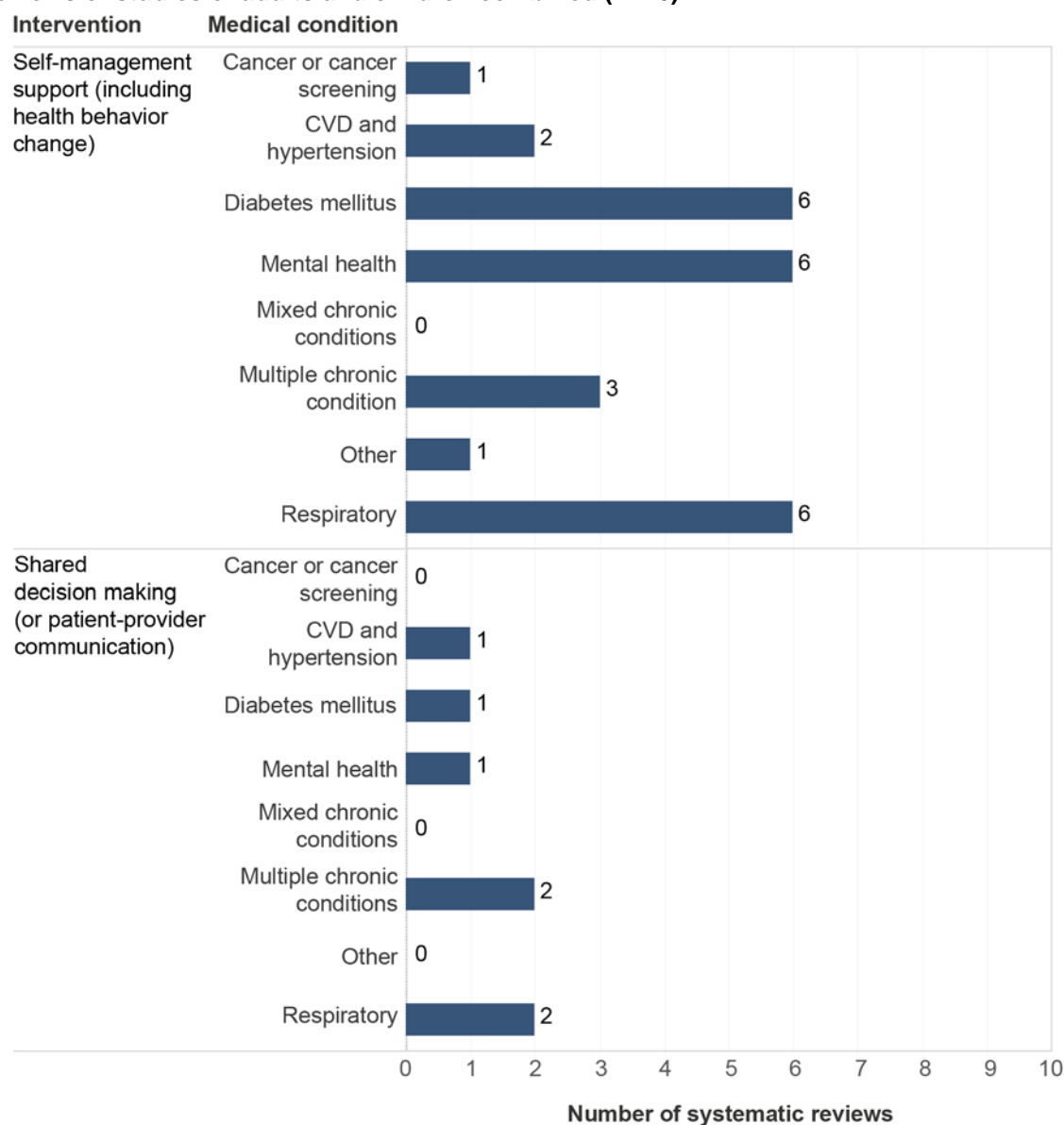
Direct Patient Care Strategies – In Reviews Including Both Adults and Children With Chronic Conditions (Guiding Question 1.a-1.c)

We identified 16 systematic reviews evaluating direct patient care engagement strategies that included children, adolescents, and adults with chronic disease. Overall, this increased the total number of reviews that included studies in pediatric populations to 30. However, given distinctions in eligibility criteria, the 16 systematic reviews presented here were analyzed separately as a “mixed” population of children, adolescents, and adults. Similar to the reviews with only children and adolescents, the most commonly studied conditions were asthma and diabetes mellitus, and the most frequently studied engagement strategies were self-management support and shared decision making. Yet, a smaller percentage of reviews (25%) included family or caregivers in their population of interest compared with those including children and adolescents alone (35.7%).

The 16 systematic reviews that reported on direct patient care engagement strategies in children, adolescents, and adults focused on a total of ten chronic diseases that spanned all age groups (Figure 13). Asthma (6 reviews)⁹⁷⁻¹⁰² and diabetes (3 reviews)¹⁰³⁻¹⁰⁵ were the most frequently studied. Four reviews included family members or caregivers,^{101,105-107} but only the systematic review by Chi and colleagues identified caregivers as their target population.¹⁰⁷ The review by Chi and colleagues was also the only systematic review in this group to specifically mention a vulnerable patient population in their results, with 23 percent of the studies focused on patients living in rural settings.¹⁰⁷ In addition, two systematic reviews included one study each that centered on vulnerable populations (rural patients or incarcerated patients).^{103,108}

Of the 16 reviews, engagement strategies primarily involved self-management support (13 reviews) and shared decision making (4 reviews).^{101,102,109,110} One review examined health literacy,¹¹¹ and one specifically mentioned advanced care planning.¹¹⁰ Four reviews cited multiple engagement strategies.^{102,104,110,111} Technology was the most frequently cited intervention modality (11 reviews). Nurses or case managers^{104,105} and coaching/educational sessions^{101,106} were examined in two reviews, each. Shared decision-making reviews primarily looked at coaching/educational sessions, although Winston and colleagues examined the use of video-based decision aids in a review of 488 studies.¹¹⁰ However, most of those studies focused on cancer or cancer screenings in adults, with only 9.5 percent of studies performed in a pediatric population.

Figure 13. Chronic medical conditions targeted in systematic reviews of different types of interventions for improving patient and family engagement at the direct patient care level, among reviews of studies of adults and children combined (n=16)

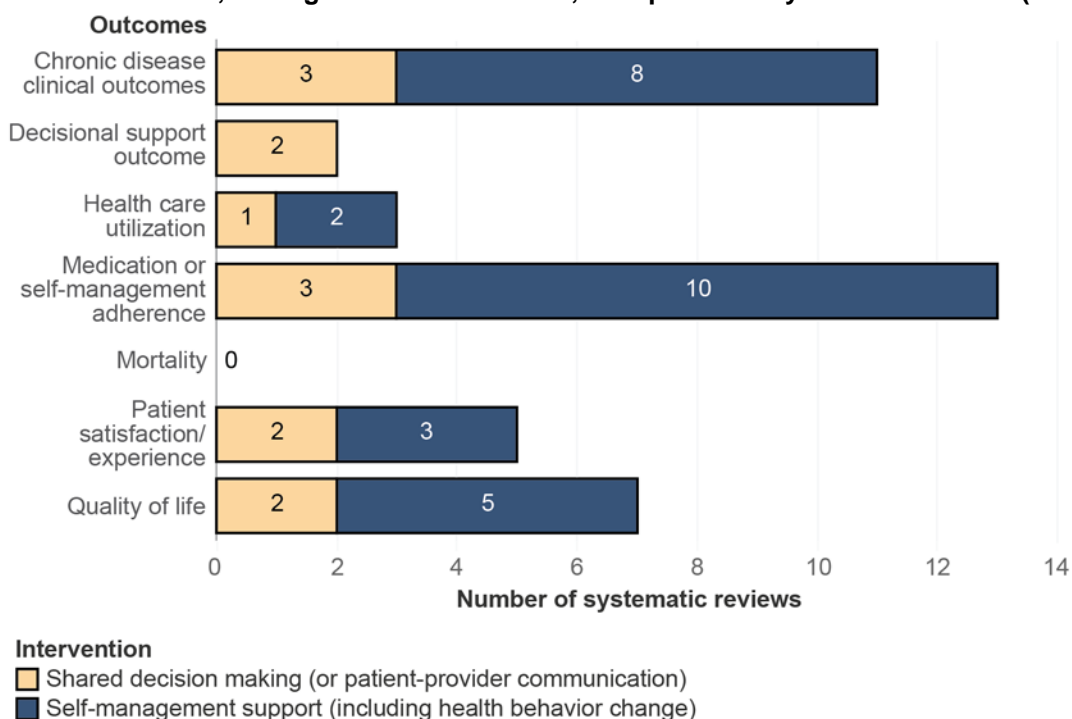


CVD =cardiovascular disease

The 16 systematic reviews of direct patient care engagement strategies in children and adolescents reported on the following engagement outcomes: medication or self-management adherence measures (13 reviews), chronic disease clinical outcomes (11 reviews), quality of life measures (7 reviews), patient satisfaction or experience (5 reviews), decisional support (2 reviews), and healthcare utilization (2 reviews) (Figure 14). As an example of a common engagement strategy for self-management support using technology, a systematic review by Kew and colleagues¹⁰⁰ examined the use of home telemonitoring on asthma symptoms for pediatric and adult patients between clinic visits with feedback by clinicians. The authors looked at 18 RCTs with multiple outcome measures for adherence, clinical outcomes, utilization, and quality of life. Only a small effect size was seen for improvement in quality of life. At least one RCT

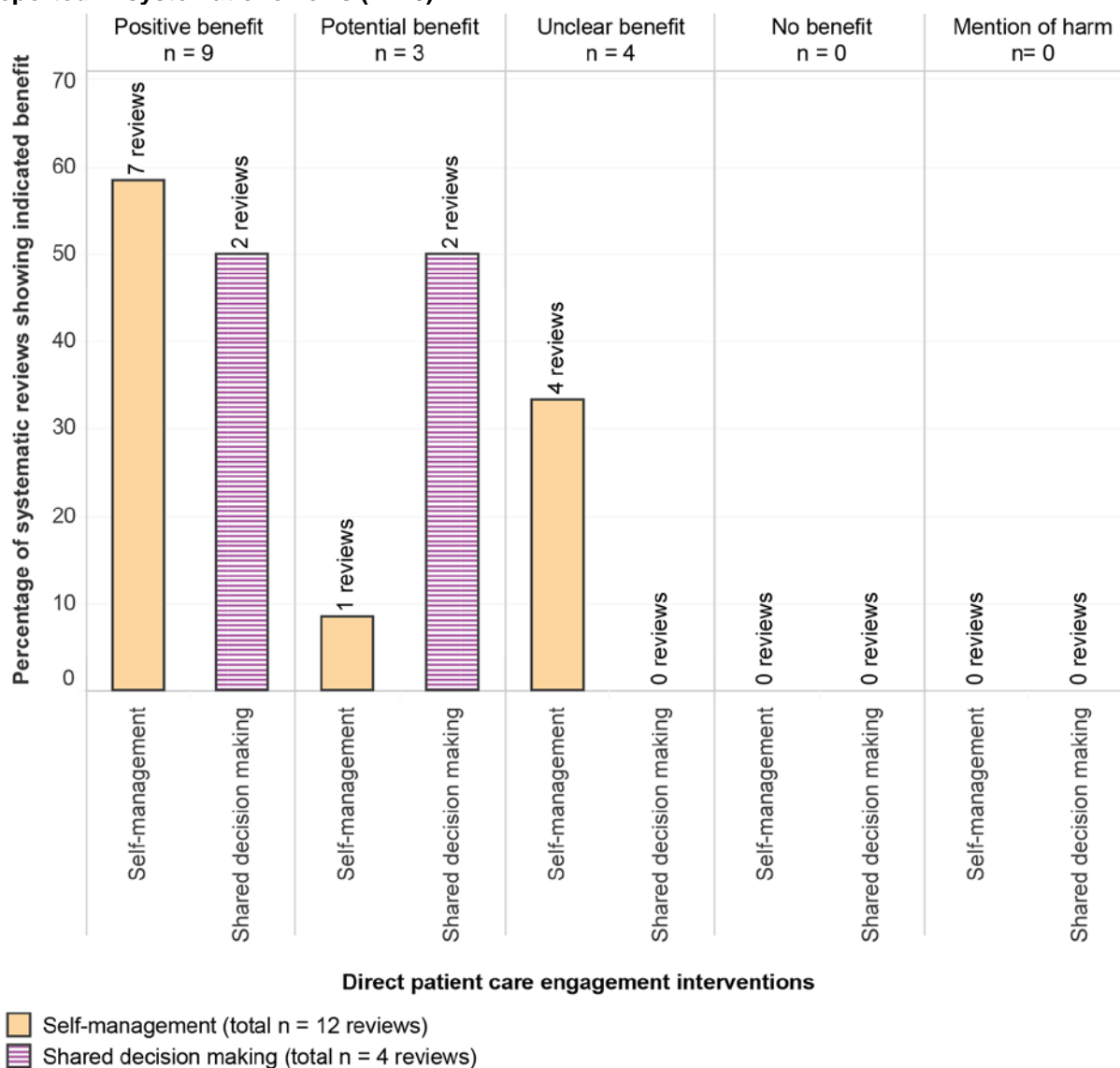
within the review examined pediatric patients and did not find any difference in control of their asthma between home telemonitoring and controls.

Figure 14. Patient and family engagement outcomes assessed for different types of direct patient care interventions, among adults and children, as reported in systematic reviews (n=16)



Overall, the 16 systematic reviews of direct patient care engagement strategies in children, adolescents, and adults showed positive effect in 9 reviews or potential benefit in 2 reviews. Five reviews showed unclear benefit.^{97,100,101,108,112} No reviews reported harms associated with patient and family engagement strategies (Figure 15).

Figure 15. Percentage of systematic reviews reporting benefits of different types of direct care patient interventions for improving patient and family engagement, among adults and children, as reported in systematic reviews (n=16)*



*Each percentage is calculated based on the total number of reviews on a given type of intervention

Table 4 depicts the findings from reviews for specific chronic health condition by type of engagement strategy in mixed population (children and adults). Reviews that focused on studies of patients with diabetes, cardiovascular disease and respiratory diseases commonly reported benefits with self-management support interventions.

Table 4. Number of systematic reviews reporting benefits among adults and children stratified by interventions and conditions

Conditions	Self-Management Support (n=12)	Shared Decision Making (n=4)	Transitional Care (or transition support) (n=0)	Other (Advanced care and health literacy) (n=0)
Overall*	● 7 ● 1 ? 4	● 2 ● 2	None	None
Diabetes	● 4 ● 1 ? 1	● 1	None	None
CVD and Hypertension	● 1 ? 1	● 1	None	None
Respiratory	● 3 ● 1 ? 2	● 1 ● 1	None	None
Cancer and cancer screening	● 1	None	None	None
Mental health	● 3 ● 1 ? 2	● 1	None	None
Other	● 1	None	None	None
Multiple chronic conditions	● 2 ? 1	● 1 ● 1	None	None
Mixed chronic conditions	None	None	None	None

- Positive benefits
- Potential benefit
- No benefit
- ? Unclear

Circle size corresponds to number of reviews reporting the type of benefit for a specific health condition.

CVD =cardiovascular disease

* Total exceeds the number for overall because reviews could be included for more than one specific condition as reported in the systematic review.

Implementation of Direct Patient Care Strategies (Guiding Question 1.d-1.f)

Three of the systematic reviews addressed implementation of direct patient care engagement strategies in adults.^{50,112,113} The systematic review by Scholl and colleagues specifically addressed organizational- and system-level characteristics that influence implementation of shared decision-making strategies.¹¹³ Only one study in the review had a comparison group,

which was at the pre-intervention phase. The review described six categories of organizational characteristics that promote implementation of engagement strategies: organizational leadership, culture, teamwork, resources, priorities, and workflow.

Of the nine systematic reviews examining the patient portal as a modality for patient and family engagement, two highlighted the implementation process for the portal.^{50,112} For example, the systematic review by Dendere and colleagues focused on the inpatient portal and identified 22 studies addressing the design and usability testing of the portal and 36 articles addressing process outcomes, such as portal adoption. They reported fewer studies that highlighted the organizational factors (e.g., leadership) that led to portal implementation.⁵⁰ The systematic review by Kruse and colleagues also highlighted the costs associated with implementation of patient portals for patient engagement and communication.¹¹²

In addition to the included systematic reviews, we identified three systematic reviews that reported on implementation outcomes.¹¹⁴⁻¹¹⁶ Systematic reviews by Anderson and Legare reported on communication (Anderson on end of life communication¹¹⁵, and Legare on shared decision making¹¹⁶). They reported barriers including the payment model, which is linked to the amount of time a provider spends with the patients, as well as six categories of “organizational leadership, culture, teamwork, resources, priorities, and workflows.”¹¹³ The systematic review by McBain and colleagues described the effect of self-management support interventions on healthcare utilization in 17 articles among patients with COPD, hypertension, and chronic heart failure, and showed increased outpatient and home visit utilization, as well as a possible decrease in hospital admissions.¹¹⁴

Health System and Organization Strategies – In Patients With Chronic Conditions (Guiding Question 1.a-1.c)

***Definition:** Health system level strategy is defined as a strategy that engages patients and families in organizational activities and/or decision-making and informs the delivery of care within a health care system, beyond the individual patient’s care (e.g., participation in an advisory committee or board membership).*

We identified five systematic reviews¹¹⁷⁻¹²¹ and three additional original articles^{97, 122, 123} that reported on patient and caregiver engagement at the health system level. The articles described specific strategies, facilitators and barriers to implementation,^{119,120} and the impact of patient engagement on health care delivery and outcomes.¹¹⁷⁻¹²¹

The health system patient and caregiver engagement strategies reported in the five systematic reviews addressed a variety of chronic conditions, most commonly mental health,^{117,119,121} cancer,^{119,121} diabetes mellitus,^{117,119} and neurologic conditions,^{119,121} as well as priority setting and improvement of care processes that were not disease-specific.^{117,121} Patient and caregiver engagement strategies most often included patients and family members, but also included representatives of community-based organizations¹¹⁷ and other community members,¹²¹ “consumers,”¹¹⁸ and “well members of the public.”¹²⁰ Most systematic reviews examined engagement within a variety of health care settings,^{117-119,121} such as hospitals or outpatient settings, although these settings were often not well described. One systematic review examined patient engagement in health care delivery in ambulatory, emergency department, or inpatient settings in hospitals.¹²⁰

Patient and caregiver engagement strategies included patient and community advisory councils,^{117,119-121} service as members of committees, participation in meetings or on project

teams,¹¹⁹⁻¹²¹ forums and workshops to provide patients with skills to support engagement,^{118,119} patients serving as instructors of trainees,¹¹⁸ and patients providing consultative input (e.g., through surveys, focus groups, or interviews).^{119,120}

These systematic reviews provide different lenses through which system level patient and family engagement can be viewed. The review by Sharma and colleagues on the impact of patient advisors¹²¹ allowed for a broad range of study designs, including qualitative research and case studies. However, the review also required an assessment of impact for one of three primary outcomes (clinical care, patient safety, or patient satisfaction) or a secondary outcome (including the impact on clinic processes, priorities, physical space, or staff or patients as advisors). This systematic review did not identify any “rigorous, prospective RCTs that assessed our primary outcomes of patient clinical care, patient safety, or patient satisfaction,” but found one cluster RCT in which “patient advisors helped clinics set priorities that were better aligned with the Patient Centered Medical Home and chronic care models.”¹²¹ Most of the included studies were case reports and observational studies which primarily described the development of material for patient education or self-management (17 studies), physical space design (15 studies), trainings for staff or trainees developed with patient engagement (10 studies), workflow or service changes (7 studies), and changes in staff awareness of patient perspectives (5 studies). Similarly, in the systematic review by Bombard and colleagues¹¹⁹ which broadly examined patient engagement strategies, the most commonly reported outcomes of patient engagement were care processes or service delivery (35 studies), policy or planning documents (15 studies), and educational materials or tool development (11 studies).

In contrast to the approaches of Sharma and Bombard, the systematic review by Oldfield and colleagues on patient, family, and community advisory councils¹¹⁷ only included studies with a comparator group, and had no limitation on the outcomes evaluated. Studies in this systematic review were categorized by the intent of the patient engagement, whether it was to inform direct care (3 studies), organizational design (3 studies), policymaking (5 studies), or health-related research (5 studies). Oldfield and colleagues similarly identified a “paucity of RCTs or high-quality observational studies.” However, they developed three “guiding principles” based on six studies that compared different aspects of patient engagement: (1) in-person and “collective” engagement is more effective than surveys, phone calls, or individual meetings; (2) patients with leadership roles in the community are more effective participants; and (3) organizational or policy recommendations made with advisory council input required a longer time and greater resources to achieve results (based on 2 studies) and might be of lower quality (based on 1 study).

Implementation of Health System and Organization Strategies – In Patients With Chronic Conditions (Guiding Question 1.d-1.f)

Two of the systematic reviews described implementation measures related to health system or organization-level patient and family engagement strategies.^{119,120} Both of these systematic reviews included multiple patient and family engagement strategies, although one was limited to care delivered in hospital-based settings.¹²⁰

Both reviews reported the importance of defining clear roles for patients and training of patients and providers or staff.^{119,120} These systematic reviews also identified provider skepticism or “negative beliefs and attitudes about patient roles and input” as barriers to successful patient engagement. Similarly, staff, provider, and/or practice awareness, interest, and engagement were significant barriers in a cluster RCT of feedback to primary care providers from patients with

significant physical disability or severe mental illness,¹²² and in a national collaborative study on patient and family collaboration in intensive care units.⁹⁷

Based on the barriers and facilitators in their systematic review,¹²⁰ Bombard and colleagues identified distinct techniques to improve patient engagement during different components of the process, including design, patient recruitment, patient involvement, creating a receptive context, and leadership actions. These techniques included ensuring diversity and representation, providing incentives to participation, using flexibility in approaches to patient and family engagement, enacting strategies to "level the playing field and [support] staff in their efforts to be partners," and demonstrating executive or institutional commitment.¹²⁰

Neither the identified reviews nor the original studies addressed fidelity in implementation or strategies to specifically support sustainment.

Community/Policy Engagement Strategies

***Definition:** Community or policy strategy is defined as a strategy that engages patients, consumers, or citizens in policymaking or that engages communities in health care policies (e.g., a hospital-neighborhood partnership to address community's concerns, disease-specific group of patients lobbying for more funding to study a rare disease, or a community group advocating for sugar-sweetened beverage or tobacco-related local policy changes to improve neighborhood public health).*

We did not find any systematic reviews on community or policy level engagement strategies, but we identified one original article that described community and policy level engagement.¹²⁴ King and colleagues described a mixed methods evaluation of a longitudinal cohort study to evaluate efforts to strengthen engagement between the Navajo National Community Health Representatives Program and the Navajo Area Indian Health Services that serve the Navajo Nation in three U.S. states. The Community Outreach and Patient Empowerment Program, in partnership with the Navajo Nation, developed a community-health system engagement intervention to improve communication and care coordination between the clinics and the community through its community health workers, with a focus on people living with uncontrolled diabetes. The program included two community advisory councils. Intermediate outcomes suggested that community health representatives perceived greater engagement with clinics through access to the client health information via the electronic health record, care coordination efforts, and direct referrals/communication with providers.¹²⁴ We did not identify any articles that described implementation of community and policy engagement strategies.

Results From the Gray Literature: Innovative Patient and Family Engagement Strategies Among Patients With Chronic Conditions

Appendix C summarizes the findings from the gray literature search, which we designed to address gaps in our review of published literature, with a particular focus on health care organization/system and community level engagement. Most of the gray literature we found focused on health system strategies that included toolkits for health care systems to facilitate the implementation of patient and family engagement strategies, including patient and family advisory councils (e.g., "Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals"). In addition, we identified several tools for health care providers and

systems to use to engage patients and families in conversations with their providers (e.g., “Supporting the Supporters: What Family Caregivers Need to Care for a Loved One with Cancer” from the Institute for Healthcare Improvement).

Guiding Question 2: What gaps exist in the current research?

In this section, we report the gaps in current research by highlighting which engagement strategies had little or no available evidence but had been identified as promising by our experts (Figure 1). In the discussion section, we will comment on the engagement strategies for which additional research is needed, or for which a new systematic review would help to synthesize current knowledge.

Figure 16 provides an evidence map that highlights the overall findings of this systematic review of patient and family engagement strategies. Figure 17 shows map of the evidence on direct patient and family engagement strategies by reported level of benefit for different types of outcomes.

We identified several major gaps. First, relatively few reviews addressed system and community/policy level strategies (5 out of 131 reviews) and even when we augmented the search to identify original studies, only three met our inclusion criteria (i.e., with a comparison group). Second, within these reviews, authors noted the absence of RCTs or high-quality observational studies of health system interventions. Third, most existing studies examined the impact of system level patient and family engagement strategies on care processes or service delivery, policy or planning documents, or educational materials or tool development. As one review noted, “objective clinical outcomes, including quality, safety, and patient satisfaction, should be assessed in order to provide a stronger evidence base for system-level patient engagement.”¹²¹ Finally, tools for standardized measurement of patient engagement would facilitate evaluation of implementation success.¹¹⁷ Despite gaps in the evidence around health system strategies, in the gray literature, we identified several toolkits aimed at increasing the uptake of these strategies (Appendix C). Second, regarding the direct patient care strategies, our Key Informants highlighted the importance of advanced care planning, but we identified relatively few (n=4) reviews focused on patient and family engagement strategies for advanced care planning.^{75,76,81,110} Third, most reviews focused on direct patient care strategies for people living with diabetes (n=45), and fewer studies focused on patients with chronic mental health conditions or multiple chronic conditions, given that 4 in 10 adults have more than 1 chronic health condition.¹²⁵ The most common chronic health conditions in the U.S. are cancer, diabetes, heart disease, Alzheimer’s disease, chronic lung disease, chronic kidney disease and stroke.¹²⁵ We identified very few studies in patients with dementia, stroke, or chronic kidney disease. The majority of systematic reviews addressing shared decision making focused on cancer screening and treatment (n=9). Fourth, few (n=13) reviews of direct patient care strategies focused on addressing their effectiveness among vulnerable populations, including urban or rural, minority, low income, or older adults. Fifth, we identified gaps in the systematic reviews reporting on implementation outcomes, health care services utilization, or cost. These outcomes are of high importance to a health system focused on value-based care and measuring cost and hospital re-admissions, but few studies measured implementation or utilization outcomes. Finally, the majority of measured outcomes involved patient surveys to assess satisfaction or HRQOL, but many reviews also addressed chronic disease clinical outcomes, particularly in the area of diabetes management. Fewer reviews addressed caregiver-related measures, even among

pediatric studies where many more interventions engaged caregivers and parents of children with chronic health conditions.

Based on our evidence map we identified a need for primary research studies to (1) develop valid and reliable measures for patient engagement, and measures for assessing the patient experience that span the continuum of care rather than assessing separate care episodes; (2) test engagement strategies with roles for family caregivers to advance self-management among both adults and children with chronic conditions; (3) test interventions for engaging patients and families in advanced care planning and end of life care; (4) develop patient portal and other technology tools that are adapted for patients with lower literacy or low technology skills to facilitate communication with medical providers; (5) measure cost-effectiveness of patient and caregiver engagement strategies to support self-management; (6) identify approaches to improve access to care, and ensure effective and quick responses to patients and family caregivers; (7) develop interventions to engage patients with multiple chronic conditions and their family caregivers in self-management of their multiple conditions.

Based on our evidence map we identified a need for more primary research studies in children and adolescents living with chronic disease to focus on (1) effective use of technology to facilitate engagement in self-management; (2) impact of engagement strategies on clinical outcomes as few studies reported clinical outcomes important to patients and families.

Based on our evidence map we identified a need for high quality primary research studies to engage patients and family caregivers at the health system and community level as overall few studies have been published. For example, studies are needed to test approaches to help (1) change medical culture so that patient and family input is prioritized and acted upon; and (2) engage patients and caregivers from diverse backgrounds and vulnerable populations and making their voice more heard within Patient and Family Advisory Councils and other platforms within healthcare organizations.

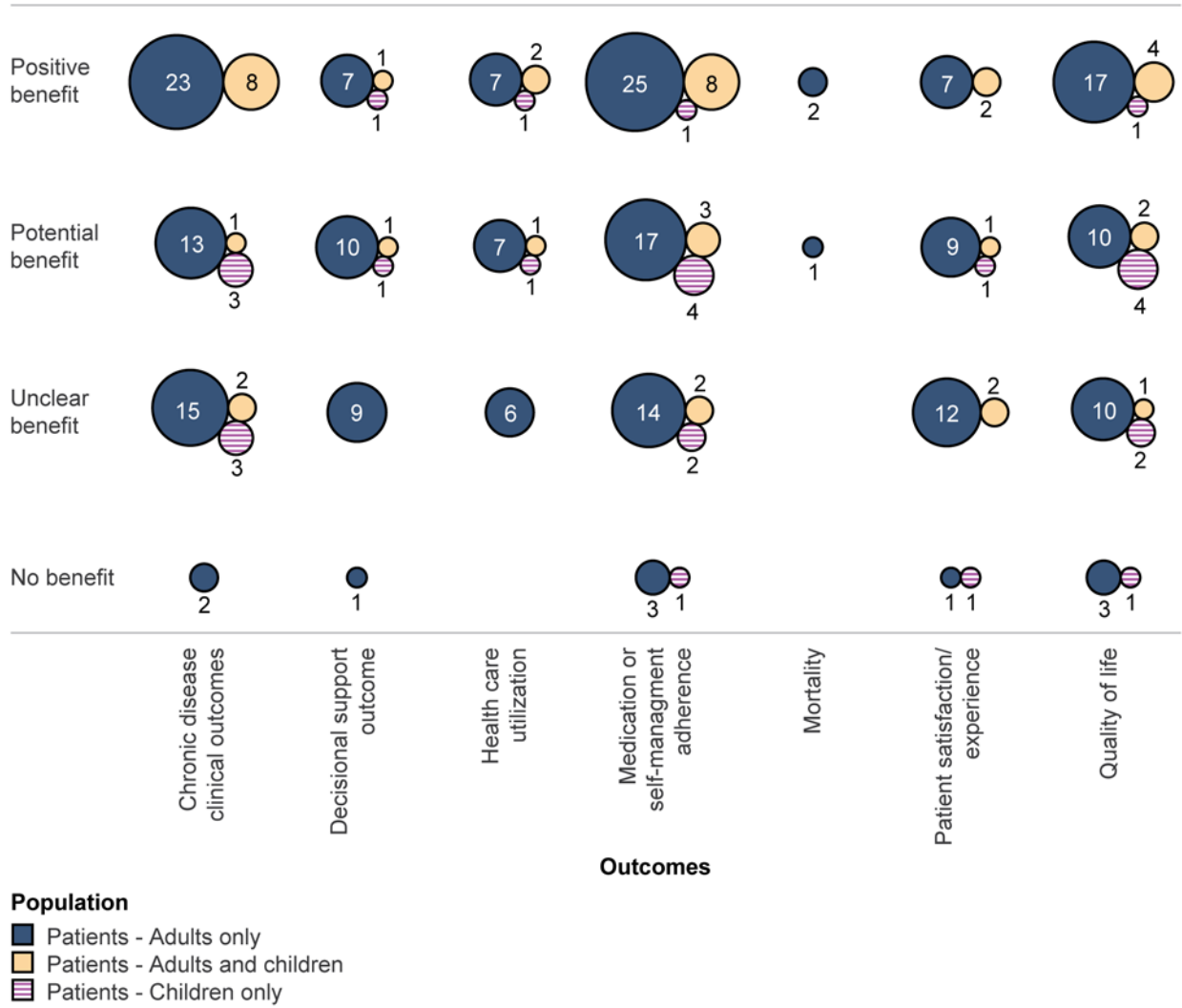
Finally, our evidence map highlights a need for both systematic review and original studies to examine implementation outcomes related to scaling and implementing direct and health system level engagement strategies. The learning health system needs to understand the fidelity, implementation, cost, and sustainability of engagement strategies.

Figure 16. Map of the evidence on patient and family engagement strategies by level of engagement



¹ Systematic review included family caregivers. The numbers in the green box (Patient populations) represent reviews.

Figure 17. Map of the evidence on direct patient and family engagement strategies by reported level of benefit for different types of outcomes



Discussion and Implications

Summary of Main Findings

Increasingly, patients, families, and caregivers play key roles not only in managing their own health and health care, but also in contributing to the development and improvement of the health care delivery system. In this Technical Brief, we built on a conceptual framework on patient and family engagement from Carman and colleagues to categorize engagement strategies into direct patient care (i.e., strategies that directly impacted individual patients' treatment or decision making), health system level (i.e., strategies with a health system impact beyond the individual patient's care), and community/policy level (i.e., strategies that engage consumers and communities in health care policies) (Figure 1).¹ In selecting articles for inclusion, we applied the broad definition of patient and family engagement by Carman and colleagues, as "patients, families, their representatives, and health professionals working in active partnership at [these] various levels across the health care system."¹ Although this definition is commonly used, the Key Informants highlighted the challenges of applying such a broad definition of patient and family engagement to the current evidence base. Their comments were consistent with the recent position paper by the American College of Physicians, "Principles for Patient and Family Partnership in Care," as what it means to do patient and family engagement vastly differs by setting, scale, and intended outcomes.³⁵ Thus, it is not surprising that we found a great deal of heterogeneity in systematic reviews of patient and family engagement strategies.

Overall, our review included 131 systematic reviews. Of these reviews, 126 focused on direct patient care (with 34 reviews on shared decision making, 88 on self-management support, and 4 on other engagement strategies). We identified only five systematic reviews and three original studies that assessed patient and caregiver engagement at the health system level. These health system-level strategies most commonly included patient and family advisory councils and committees. We found only one original study and no systematic reviews on patient and family engagement at the community level. Of the five systematic reviews and three original articles focused on patient and family engagement at the health system level, patient and family advisors or advisory councils were the focus of two systematic reviews,^{117,121} while three reviews examined system level patient and family engagement through a variety of other strategies, including participating in meetings, committees, and project teams,¹¹⁹⁻¹²¹ or providing consultative input through surveys, focus groups, or interviews.^{119,120} Health system level reviews demonstrated some benefits, such as improvements in health care processes, development of organizational plans and policies, and education or tool development primarily in descriptive studies. The one article focused on a community patient engagement strategy highlighted a neighborhood-clinic partnership in the Navajo Nation. The partnership aimed to increase community health worker engagement with healthcare services to improve care for patients with diabetes, which has a high burden of disease on their community.¹²⁴

The 126 systematic reviews on direct-care patient engagement strategies varied in terms of populations (14 in children, 16 in adults/children, 96 in adults only) and chronic diseases (diabetes was most commonly studied), and clinical settings and modalities for engagement (e.g., health coaches, mobile applications). Despite a high volume of studies addressing direct-patient care engagement strategies, fewer systematic reviews focused on the engagement of vulnerable patient populations. The most common direct patient care engagement strategies included team-based care to support patient self-management, patient-provider communication using shared decision making, as well as mobile health and electronic health record tools to improve engagement. Among adult patients, the most promising and innovative strategies with the highest volume of evidence (i.e., several large RCTs) included group-based educational programs to

promote chronic disease self-management by peers and other healthcare professionals,¹²⁶ web-based and short message service interventions for cancer survivors,⁵⁹ promising telehealth programs to promote communication, self-monitoring and counseling,¹²⁷ as well as mobile health to promote weight loss.¹²⁸ Among pediatric patients, the most promising and innovative direct-patient care engagement strategies included: eHealth tools for symptom control in adolescents with asthma;⁹⁸ transitions of care support through combined care coordination and family education sessions at hospital discharge;⁸⁶ and shared decision making with decision aids,⁸⁹ especially for mental health treatment.⁸⁷ Importantly, these strategies required consideration of the child's age and developmental level, but also standard educational components as reported by Saxby and colleagues.⁹²

Strengths and Limitations of Our Evidence Map

To our knowledge, this is the first systematic review to address patient and family engagement strategies focused on health system level and community/policy level strategies, in addition to direct patient and family engagement strategies. Similar to our review, the systematic review by Coulter and colleagues included direct-patient care engagement strategies.¹²⁹ Like the Coulter review, we identified many patient and family engagement reviews focused on self-management support and education, as well as clinical decision making through patient-provider communication strategies.¹²⁹ Sharma and colleagues conducted a review of patient and family engagement strategies specifically related to patient safety and identified only one review with a health system level engagement strategy.¹³⁰ Despite the large number of direct patient care engagement studies, we identified inconsistent findings for the benefits of some self-management and communication strategies, even within the same chronic disease condition. The inconsistency was in part owing to the heterogeneity of tested interventions, different measures, and low quality of the original studies.

Given the widespread implementation of electronic health records and the proliferation of mobile phone applications in recent years, a major contribution of our review was the identification of 49 systematic reviews focused on using technology (mobile health, electronic health records, Web-based programs) as part of the engagement strategy. One systematic review, by Irizarry and colleagues,⁷⁷ included 122 articles (14 RCTs) and focused on patient engagement using the electronic health record. This descriptive review identified five major topics related to patient engagement using the electronic medical record (patient adoption, provider endorsement, health literacy, usability, and utility) and, highlighted that use of patient portals was influenced by patients' age, ethnicity, education level, health literacy, health status, and role as a caregiver. Health care delivery factors, mainly provider endorsement and patient portal usability, also contributed to patients' ability to engage through and with the patient portal.⁷⁷ Only one systematic review, by Kuo and colleagues, reported on a clinical outcome related to the effect of secure messaging in the patient portal on diabetes outcomes.⁵³ This review identified one RCT, which showed a decrease in hemoglobin A1c among patients with uncontrolled diabetes at 6 months but not at 12 months.^{53,131}

We also have identified several limitations of our review and evidence map. First, because of the broad definition of patient and family engagement, we focused on identifying and synthesizing findings from systematic reviews, rather than original articles for direct patient-care strategies, which made it less feasible to capture details about each study's population, intervention, and barriers to implementation. We were not able to extract the detail information from the studies included in the systematic reviews. This is particularly important because we were unable to directly capture whether vulnerable populations were included within each study and had to rely on the information provided by the review. In addition, this resulted in heterogeneity of interventions along the continuum of engagement within some reviews, which

may account for some of the inconsistent findings in our results. Also, at the direct care level, we were also unable to provide a granular description of the tested interventions, and instead summarized them by modality and disease area. Second, we excluded articles and reviews explicitly focused on patient engagement for the purposes of research, especially around research prioritization or on community advisory boards focused on research. This exclusion has important implications as, increasingly, the learning health system is blending research with continuous quality improvement with similar goals of improving health care quality, safety, and delivery. In addition, community-based participatory research has a long tradition of engaging patients, communities, and stakeholders in research that is driven by and sustained within the community. We acknowledge that many patient and family engagement strategies are being used in community-based participatory research, and that there is often a blending between engagement for patient care and for research on improving the delivery of patient care. Third, we focused on engagement of patients with chronic health conditions, and therefore excluded reviews and articles that only focused on chronic disease prevention (e.g., increasing exercise by using a mobile application). Owing to the importance of population health initiatives focused on wellness and prevention, future reviews could address this gap by understanding the patient and family engagement strategies for staying well and preventing chronic disease. Fourth, we did not assess the risk of bias in the original studies included in the systematic reviews or in the additional original studies we found. Fifth, because of the scope of this project including direct patient care to community level engagement strategies, we may have missed examples of community and policy level engagement, as few of these articles met inclusion criteria for having a comparison group or including outcomes of interest.¹³²⁻¹⁴¹

Implications for Clinical Practice, Education, and Health Policy

The learning health system is defined by the AHRQ as “a health system in which internal data and experience are systematically integrated with external evidence, and that knowledge is put into practice.”¹⁴² Because one of the principles of the learning health system is to “promote the inclusion of patients as vital members of the learning team,” it is important to identify best practices and high quality evidence to select strategies that not only engage patients but also lead to improvements in care quality and value. The American Institute for Research created a Roadmap for Patient and Family Engagement in Healthcare Practice and Research to assist health care systems and providers in partnering with patients and families.¹⁴³ They described best practices of strategies that healthcare systems are currently using. Despite the enthusiasm about increasing patient engagement at a systems level and calls to make it an expectation, our review identified a paucity of rigorous studies about the effectiveness and implementation of health system strategies, making it challenging to recommend wide uptake. In addition, our review aimed to describe barriers and facilitators to implementing patient and family engagement strategies in clinics and hospitals. However, because few systematic reviews specifically addressed or reported implementation outcomes, it is unclear which are the best and most effective processes for engaging patients who have diverse voices, ultimately to inform improvements in health care delivery. Explicit development of a theoretical framework for understanding the key elements of a system level patient and family engagement strategy could help guide implementation, measurement development, and evaluation.

Future Research Needs

More reviews are needed that are focused on patients with chronic mental health conditions and those with multiple chronic conditions particularly given the vulnerability and risk of poor

outcomes for these patients. Also, more reviews are needed that focus on children and adolescents living with chronic disease. The systematic reviews at the health system level consistently highlighted a need for high quality studies with robust study designs to evaluate patient and organizational level outcomes. Some studies highlighted barriers to high quality evidence, which included the heterogeneity of both the intervention and outcomes studied, as well as limited tools for measuring patient engagement. In fact, a recent systematic review, by Dukhanin,¹⁴⁴ reported on measurement and evaluation tools for the assessments of patient, public, consumer, and community engagement in organization-, community-, and system-level healthcare decision making. Most of these diverse 23 tools used surveys that assessed the process of engagement, as well as the impact of engagement participants (e.g., improved knowledge) on the services provided by the organization or system (e.g., improved quality or decreased utilization of services) and on the organization (e.g., redesign of staff roles, or staff training policies).¹⁴⁴ There is a need for measures to assess to what extent health systems are supporting the engagement of patients and caregivers. In terms of measures of patient experience, there are models for engaging patients and families in the development of these measures in order to include questions that address what patients care about most and how they would like to be engaged in their care.¹⁴⁵ In addition, few studies rigorously evaluated health system interventions using health services design methods that included a comparison group. Future study design and analysis methods could include interrupted time series and propensity score approaches.¹⁴⁶ As more evidence emerges on patient and family engagement strategies at the health system level, it will become necessary to synthesize that evidence. Synthesis will be challenging because the strategies are likely to be highly variable in the nature of the populations, interventions, comparisons, and outcomes studied.

We also identified future research needs to improve direct patient care strategies. The majority of the evidence on direct patient care strategies for patient and family engagement among patients with chronic disease is in the area of self-management support. Further study is needed to assess impact of strategies to improve shared decision making and patient-provider communications on clinical outcomes. In addition, despite a great deal of discussion by the Key Informants about the importance of patient and family engagement to support advanced care planning, we found a large gap in evidence on the effectiveness of engagement strategies focused on advanced care planning for patients with chronic conditions.

Among the systematic reviews of direct patient care interventions in adults, 8 reviews included patients with multiple chronic conditions (5 with self-management support interventions, one with shared decision-making intervention and 2 with transitional care interventions) (Table 2 and Figure 7). Five of the 8 were deemed to have positive benefit, indicating an important area for future research in identifying which of these interventions have the highest level of evidence and could potentially be more widely implemented.

The role of family and caregivers is particularly relevant to efforts to improve engagement among subpopulations including older adults and people with impaired decision-making capacity (e.g. patients with dementia). However, few reviews were able to examine the sub-populations included in the studies. Future studies need to provide details about their target populations to permit better assessment of the applicability of strategies to all patients and communities. Future studies are needed to assess risks and benefits of engagement including patient anxiety (increase or decrease), as well as disproportionate access to engagement methods, which could worsen health disparities. However, outside of the pediatric articles, few studies in adults included family caregivers or measured caregiver-related outcomes, highlighting an important research gap. In the pediatric population, more studies are needed to assess the effectiveness of engagement strategies on clinical outcomes, as most studies focused only on patient-reported outcomes. More pediatric studies are needed to examine the effect of technology among children

and adolescents living with chronic disease, as these strategies were not as well studied in children, compared with the adult population. In addition, most pediatric studies addressed children with lower medical complexity or single chronic diseases (like asthma), indicating that more rigorous studies are needed to study patient and family engagement among families with children that have medically complex health conditions. New evidence synthesis will be needed as evidence grows on the effectiveness of patient and family engagement strategies for pediatric conditions and advanced care planning. As indicated above, synthesis will be challenging because of expected heterogeneity in the populations, interventions, comparisons, and outcomes studied.

Conclusion

In conclusion, we identified a wealth and diversity of evidence on direct patient care engagement strategies for adults with chronic conditions, but a dearth of evidence for strategies at the health system and community/policy levels. Patient and family engagement strategies with the greatest evidence pertain to self- management support. We identified inconsistent findings among reviews of self-management strategies, even within the same chronic condition. This is in part due to the heterogeneity of tested interventions, different measures, and low quality of the original studies. Use of technology to facilitate patient and family engagement is a promising approach. Few studies examined engagement strategies for advanced care planning or interventions for patients with multiple chronic conditions. The evidence on engagement strategies in the pediatric population is limited by a small number of systematic reviews and few reporting on clinical outcomes. More research is needed to address a big gap in evidence on patient and family engagement at the health system and community/policy levels. Such research should use robust study designs, such as cluster RCTs, assessing the impact on clinical outcomes and patient satisfaction, and using standardized tools to measure the impact on patient and family engagement.

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Appendix A. Search Strategies

PubMed Search

#	String
1. Population	Patient Participation[Mesh] OR "patient participation"[tiab] OR "patient engagement" [tiab] OR "patient involvement" [tiab] OR "patient empowerment" [tiab] OR "patient partnership" [tiab] OR "patient activation" [tiab] OR "patient-activated" [tiab] OR "family participation"[tiab] OR "family engagement" [tiab] OR "family involvement" [tiab] OR "family empowerment" [tiab] OR "family partnership" [tiab] OR "family activation" [tiab] OR "consumer participation"[tiab] OR "consumer engagement" [tiab] OR "consumer involvement" [tiab] OR "consumer empowerment" [tiab] OR "consumer partnership" [tiab] OR "consumer activation" [tiab] OR "caregiver participation"[tiab] OR "caregiver engagement" [tiab] OR "caregiver involvement" [tiab] OR "caregiver empowerment" [tiab] OR "caregiver activation" [tiab] OR "patient context" [tiab] OR "patient capacity" [tiab] OR "patients capacity" [tiab]
2. Intervention	Advisory Committees [Mesh] OR PFAC [tiab] OR "patient council" [tiab] OR "patient committee"[tiab] OR "patient advisor" [tiab] OR "family council" [tiab] OR "consumer council" [tiab] OR "family advisor" [tiab] OR "advisory council" [tiab] OR "community advisory" [tiab] OR Self-Management [mh] OR "Self-Management" [tiab] OR "Self Management" [tiab] OR Shared Decision Making [mh] OR "decision making"[tiab] OR "decision-making" [tiab] OR "Speaking up" [tiab] OR telemedicine [mh] OR Electronic Health Records [mh] OR "Electronic Health Records" [tiab] OR "Medical Informatics"[mh] OR "health informatics"[tiab] OR "mobile health" [tiab] OR "eHealth" [tiab] OR "digital health"[tiab] OR "smart phone"[tiab] OR "mobile app"[tiab] OR "mobile applications"[tiab] OR "mHealth"[tiab] OR "smartphones" [tiab] OR Patient Portals [mh] OR "Patient Portals" [tiab] OR Patient Access to Records [mh] OR "Patient Access to Records"[tiab] OR "Opennotes" [tiab] OR Health Literacy [mh] OR literacy [tiab] OR hospice [tiab] OR palliative [tiab] OR "end-of-life" [tiab] OR "end of life"[tiab] OR terminal care [mh] OR Palliative Care [mh] OR "patient safety"[tiab] OR "decision support"[tiab] OR Advance Care Planning [mh] OR "Advance Care Planning" [tiab] OR "Advance Directives" [tiab] OR "peer support"[tiab] OR "social support"[tiab] OR "family support"[tiab] OR "healthcare professional support" [tiab] OR "patient navigator" [tiab] OR Accountable Care Organizations[mh] OR Population Health Management [MH] OR "Accountable Care Organizations"[tiab] OR "Population Health Management" [tiab]

#	String
1 AND 2	((Patient Participation[Mesh] OR "patient participation"[tiab] OR "patient engagement" [tiab] OR "patient involvement" [tiab] OR "patient empowerment" [tiab] OR "patient partnership" [tiab] OR "patient activation" [tiab] OR "patient-activated" [tiab] OR "family participation"[tiab] OR "family engagement" [tiab] OR "family involvement" [tiab] OR "family empowerment" [tiab] OR "family partnership" [tiab] OR "family activation" [tiab] OR "consumer participation"[tiab] OR "consumer engagement" [tiab] OR "consumer involvement" [tiab] OR "consumer empowerment" [tiab] OR "consumer partnership" [tiab] OR "consumer activation" [tiab] OR "caregiver participation"[tiab] OR "caregiver engagement" [tiab] OR "caregiver involvement" [tiab] OR "caregiver empowerment" [tiab] OR "caregiver activation" [tiab] OR "patient context" [tiab] OR "patient capacity" [tiab] OR "patients capacity" [tiab])) AND (Advisory Committees [Mesh] OR PFAC [tiab] OR "patient council" [tiab] OR "patient committee"[tiab] OR "patient advisor" [tiab] OR "family council" [tiab] OR "consumer council" [tiab] OR "family advisor" [tiab] OR "advisory council" [tiab] OR "community advisory" [tiab] OR Self-Management [mh] OR "Self-Management" [tiab] OR "Self Management" [tiab] OR Shared Decision Making [mh] OR "decision making"[tiab] OR "decision-making" [tiab] OR "Speaking up" [tiab] OR telemedicine [mh] OR Electronic Health Records [mh] OR "Electronic Health Records" [tiab] OR "Medical Informatics"[mh] OR "health informatics"[tiab] OR "mobile health" [tiab] OR "eHealth" [tiab] OR "digital health"[tiab] OR "smart phone"[tiab] OR "mobile app"[tiab] OR "mobile applications"[tiab] OR "mHealth"[tiab] OR "smartphones" [tiab] OR Patient Portals [mh] OR "Patient Portals" [tiab] OR Patient Access to Records [mh] OR "Patient Access to Records"[tiab] OR "Opennotes" [tiab] OR Health Literacy [mh] OR literacy [tiab] OR hospice [tiab] OR palliative [tiab] OR "end-of-life" [tiab] OR "end of life"[tiab] OR terminal care [mh] OR Palliative Care [mh] OR "patient safety"[tiab] OR "decision support"[tiab] OR Advance Care Planning [mh] OR "Advance Care Planning" [tiab] OR "Advance Directives" [tiab] OR "peer support"[tiab] OR "social support"[tiab] OR "family support"[tiab] OR "healthcare professional support" [tiab] OR "patient navigator" [tiab] OR Accountable Care Organizations[mh] OR Population Health Management [MH] OR "Accountable Care Organizations"[tiab] OR "Population Health Management" [tiab])
4. Limit 2015 - present	Filters activated: Publication date from 2015/01/01 to Present
5. Limit to systematic reviews	#4 AND Cochrane validated systematic review search
6. Original articles without systematic reviews	#4 AND without Cochrane validated systematic review search

Appendix B. Evidence Tables

Direct Patient Care

Evidence Table 1. Study characteristics of included systematic reviews addressing direct patient care

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
Advanced Care Planning – Adult Only	Coulter, 2015 ¹	To assess the effects of personalized care planning for adults with long-term health conditions compared to usual care (i.e. forms of care in which active involvement of patients in treatment and management decisions is not explicitly attempted or achieved).	Inception-2013	We included randomized controlled trials and cluster-randomized trials involving adults with long-term conditions where the intervention included collaborative (between individual patients and clinicians) goal setting and action planning	We excluded studies where there was little or no opportunity for the patient to have meaningful influence on goal selection, choice of treatment or support package, or both.	Total: 19 RCTs: 19 Non-RCTs with comparison: 0 Observational: 0	Outpatient clinics

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
Health Literacy – Adult Only	Schaepe, 2015 ²	To review the current literature on educational interventions used in peritoneal dialysis (PD).	2006-2013	(1) Types of participants: adult participants (>18 years), (a) training others in PD and (b) receiving PD training themselves; (2) Types of intervention: educational interventions; (3) Types of outcome measures: no limitations were imposed on outcome measures (4) Study design: systematic reviews, meta-analyses, primary qualitative and quantitative research studies (5) Setting: clinical or home (6) Publication: academic journal (peer reviewed) (7) Language: English or German	(1) Studies focusing on hemodialysis, studies focusing on both hemodialysis and peritoneal dialysis; (2) Case studies or very small samples n < 6; (3) Quantitative studies using descriptive methods and non-statistical methods; (4) Studies without education	Total: 18 RCTs: 2 Non-RCTs with comparison: 0 Observational:16	Inpatient, outpatient clinics, home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
Self-Management Support – Children Only	Bal, 2015 ³	To systematically explore the effectiveness and effective components of self-management interventions	2000-2015	RCT; English, 2003-2015; studies focusing on the evaluation of SMI and describing the SMI or referring to previous description(s) of the intervention; Outcome measures: studies considering clearly defined outcome measures; Participants: studies focusing on young people aged 7–25 years with somatic chronic conditions or physical disability. The age of seven years is considered a developmentally appropriate age to start the development of independence. As young adults are still developing their full potential, the age range was extended from 18 to 25 years.	None listed	Total:42 RCTs:42 Non-RCTs with comparison:0 Observational:0	Clinics, home, school, camps
	Low, 2019 ⁴	This study aimed to evaluate the current evidence on Web- or mobile-based interventions designed for adolescent and young adults.	1967-2019	i.No restrictions on the study design, ii. Intervention must be freely available on device or web page iii. Participants aged < 18 years or ≥18 years with chronic diseases	Unclear indication for pediatrics vs adults interventions.	Total:29 RCTs:6 Non-RCTs with comparison:2 Observational:21	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Saxby, 2018 ⁵	To articulate the components of educational interventions that help children learn about managing their asthma, cystic fibrosis, or diabetes, relevant to their age/developmental status	Not mentioned- 2018	Studies were included if they were published before 27 January 2018, and if they focused on children and adolescents (aged 20 years) with asthma, T1DM, or CF as active participants in the CCSM education strategy.	Studies were excluded if they focused on adults, other childhood conditions, or if they did not contain age/ developmentally based CCSM education components.	Total:30 RCTs:23 Non-RCTs with comparison:1 Observational:6	School, hospital, home
	Knafl, 2017 ⁶	Based on a sample of 70 interventions for families in which there was a child with a chronic physical condition, this analysis examined the nature of family engagement in the interventions	2000-2014	(a) Randomized clinical trial (RCT) design; (b) published in an English- language journal between January 1, 2000, and March 31, 2014; and (c) intervention included families in which a child less than 19 years old had a CPC.	None listed	Total:93 RCTs:93 Non-RCTs with comparison:0 Observational:0	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Campbell, 2016 ⁷	To evaluate the effectiveness of interventions designed to improve the transition of care for adolescents from pediatric to adult health services	Inception-2015	Randomized controlled trials (RCTs), controlled before- and after-studies (CBAs), and interrupted time-series studies (ITSs); We included adolescents with conditions that required ongoing clinical care, who would be leaving pediatric services and would require on-going services in adult healthcare units, or had already transferred to adult services, and their families, parents, or guardians	None listed	Total:4 RCTs:4 Non-RCTs with comparison:0 Observational:0	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Majeed-Ariss, 2015 ⁸	To systematically review the literature on the effectiveness of mobile apps designed to support adolescents' management of their physical chronic or long-term conditions.	2003-2015	Adolescents aged 10-24 years; diagnosed with chronic physical conditions in any setting; Any app for a mobile phone or tablet that could be considered a management intervention (or a component of an intervention) in terms of content and/or delivery; Intervention versus usual care or intervention variant versus intervention variant or pre and post; Randomized controlled trial (RCT) or controlled clinical trial or cohort analytic study or case-control study or cohort study or interrupted time series.	Non-English-language publications and studies that focused on adolescents with mental health problems, learning disabilities, and/or cognitive impairment were excluded due to resource limitations. Interventions using mobile phone technology only in the context of delivering/receiving text messages or phone calls were also excluded.	Total:4 RCTs:1 Non-RCTs with comparison:0 Observational:3	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Charlier, 2015 ⁹	To conduct a systematic review and meta-analysis of randomized controlled trials assessing the effectiveness of serious games in improving knowledge and/or self-management behaviors in young people with chronic conditions.	1990-2004	1) RCTs that compared a digital game (serious game or commercial) with either standard education or no specific education, 2) a study population of children or adolescents with chronic conditions at any stage of disease, and 3) a quantitative assessment of patients' knowledge and/or self-management as one of the outcomes variables.	Articles referring to computer game interventions in relation to health promotion programs in preventive healthcare; focusing on symptom management or distraction without measuring behaviors; focusing on measurement and diagnostic methods; and on game theory, game development, and evaluation were excluded.	Total:9 RCTs:9 Non-RCTs with comparison:0 Observational:0	Hospital and home
	Sattoe, 2015 ¹⁰	To provide a systematic overview of self-management interventions (SMI) for young people with chronic conditions with respect to content, formats, theories, and evaluated outcomes.	2003-2014	Original research articles in English, published from 2003-2014; ages 7-25 with somatic chronic disease or disability; studies focusing on the evaluation of an SMI and describing the SMI or referring to previous description(s) of the intervention	None listed	Total:86 RCTs:45 Non-RCTs with comparison:29 Observational:12	Home, clinic, hospital, camp, online

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Hamline, 2018 ¹¹	Which pediatric hospital discharge interventions affect health care use or parental satisfaction with care	Inception-2017	Inclusion criteria were: (1) available in English, (2) focused on children <18 years of age, (3) pediatric data reported separately from adult data, (4) not focused on normal newborns or pregnancy, (5) discharge intervention implemented in the inpatient setting, and (6) outcomes of health care use or caregiver satisfaction.	Reviews, case studies, and commentaries were excluded.	Total:31 RCTs:5 Non-RCTs with comparison:25 Observational:1	Hospital
	Clemente, 2016 ¹²	Identify existing models of transitional care in rheumatic and musculoskeletal diseases (RMD), describe their strengths and weaknesses, and provide support to a consensus initiative to develop recommendations for transitional care.	Inception-2014	Studies were selected if they described valid transition programs in jRMDs. The term valid referred to programs that had been described in sufficient details as to be reproducible and had been implemented and tested in real life conditions).	None listed	Total:27	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
Self-Management Support – Adults and Children	Niznik, 2018 ¹³	Identify the impact of clinical pharmacist telemedicine interventions on clinical outcomes, subsequently defined as clinical disease management, patient self-management, and adherence, in outpatient or ambulatory settings	Inception-2016	Pharmacist interventions; outpatient or ambulatory settings	Studies of non-clinical outcomes (i.e. dispensing or product preparation) and with no comparator were excluded	Total:34 RCTs:17 Non-RCTs with comparison:17 Observational:0	Hospital
	Barello, 2016 ¹⁴	This paper aimed at reviewing findings from the literature about the use of eHealth in engaging patients in their own care process	2004-2014	The eHealth actions described must have been performed for the engagement of patients (technologies applied to engage other health stakeholders such as medical staff, hospital managers, or others were excluded); The intervention had to feature at least one group of participants (single cases excluded); both between and within groups designs were considered; The intervention had to assess one or more variables connected to patient engagement.	The interventions used not well-specified technologies, or the technologies used were not clearly internet-based (i.e., telephone); (2) the terms “patient engagement,” or “patient activation” were actually present in the paper, but there were not referenced	Total:11 RCTs:3 Non-RCTs with comparison:1 Observational:7	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Bashi, 2018 ¹⁵	To investigate smartphone-based educational interventions and their structures and strategies for patient self-management.	2006-2016	Peer-reviewed studies, Primary or secondary studies reporting clinical trials.	Conference abstracts, book reviews, letters, editorials, case reports and unpublished studies were excluded	Total:15 RCTs:6 Non-RCTs with comparison:0 Observational:11	Home
	Lycett, 2018 ¹⁶	Examine the use and application of theory in the development of digital interventions to enhance asthma self-management and to evaluate the effectiveness of theory-based interventions in improving adherence, self-management, and clinical outcomes	Not mentioned- 2017	Paper in English; Patients with asthma; Empirical study (pilot, feasibility, or evaluative study); Intervention focused on patient (rather than physician or carer); Digital intervention (eg, online intervention, smart phone app, electronic monitor, short message service (SMS), interactive voice recognition, or wearable; Intervention designed to enhance adherence or persistence with asthma medication or self- management; Explicit mention of the use of theory to design the self-management intervention or to increase engagement with the intervention	Conference abstracts; Paper not in English; Review or letter; Intervention is delivered to parent(s) of children with asthma Not an empirical study; Clinician focus (clinician attitude, behavior, or diagnostic tool); Intervention not designed to enhance	Total:14 RCTs:10 Non-RCTs with comparison:0 Observational:4	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Lancaster, 2018 ¹⁷	Determine the impact of patients' use of eHealth tools on self-reporting adverse effects and symptoms that promote changes to medication use	2000-2018	eHealth tool must have allowed patients (or caregivers) to enter information directly (as opposed to information being entered by a health care provider); included self-reporting functionalities focusing on medication monitoring, contain a medication monitoring or use component, or specifically incorporating the option for the patient or caregiver to enter symptoms including adverse effects; and needed to focus specifically on medication use, clinical outcomes, or symptom reporting following use of the eHealth tool	Exclusion criteria were conference abstracts; qualitative studies; without a comparator group; did not report on at least one medication-related outcome; self-management strategies focused on lifestyle modification, behavioral interventions, or nondrug interventions; focused solely on the validation of an eHealth tool; focused on methodological or technical aspects of eHealth interventions; containing nonempirical information; synthesized information about multiple eHealth tools in an article; and eHealth tools used by regulatory agencies to report adverse drug events (ADEs)	Total:14 RCTs:13 Non-RCTs with comparison:1 Observational:0	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Kew, 2016 ¹⁸	To assess the efficacy and safety of home telemonitoring with healthcare professional feedback between clinic visits, compared with usual care for asthma	1992-2016	We included parallel randomized controlled trials (RCTs) of adults or children with asthma in which any form of technology was used to measure and share asthma monitoring data with a healthcare provider between clinic visits, compared with other monitoring or usual care.	We excluded trials in which technologies were used for monitoring with no input from a doctor or nurse	Total:18 RCTs:18 Non-RCTs with comparison:0 Observational:0	Home
	Graham, 2016 ¹⁹	This systematic review aimed to: collate all ACT interventions with chronic disease/long-term conditions, evaluate their quality, and comment on efficacy	Inception-2015	Studies were included if they described an ACT intervention applied to a long-term condition	1) were not published in English; 2) described a hypothetical intervention; 3) did not clearly use ACT techniques; 4) were undertaken with a chronic pain population or mental health population; 5) were designed to prevent illness in a group without a long-term condition; or 6) were used to manage symptoms where evidence for causative biological pathology is unclear	Total:18 RCTs:10 Non-RCTs with comparison:0 Observational:8	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Yin, 2019 ²⁰	This study aimed to characterize the different tasks and contexts in which context-aware systems for patient work were used as well as to assess any existing evidence about the impact of such systems on health-related process or outcome measures.	Not mentioned-2017	Chronic conditions, involved the use of a context-aware system to support patients' health-related activities, and reported the evaluation of the systems by the users	Not in English; focused on health care providers instead of consumers; interventions that merely gathered and displayed context information, without using it to adapt system behavior (passive context awareness)	Total:6 RCTs:0 Non-RCTs with comparison:0 Observational:6	Home
	Chi, 2015 ²¹	The present study aimed to systematically review evidence on the effect of telehealth applications on family caregivers	Not mentioned-2014	Studies were included if they used any telehealth interventions and focused on family caregivers' outcomes	Studies were excluded if they were not published in English, did not involve human subjects or did not employ a telehealth intervention	Total:65 RCTs:19 Non-RCTs with comparison:33 Observational:14	Hospital and home
	Hill, 2015 ²²	To systematically review health coaching interventions regarding effectiveness of health coaching for specific outcomes, optimal intervention approaches, and identification of specific techniques associated with effectiveness.	2000-2012	We included RCTs that used health coaching to influence health-related outcomes or processes. Participants of any age were included and outcome measures were not limited in any way, nor was the method in which health coaching was administered (e.g., via telephone, Internet, in person).	Studies that did not report their outcome measures were excluded (e.g., feasibility studies). Papers were limited to those in English published between January 2000 and October 2012.	Total:16 RCTs:16 Non-RCTs with comparison:0 Observational:0	Hospital and home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Pamungkas, 2017 ²³	This SR aimed to describe the impact of Diabetes Self Management Education that involves family members on patient outcomes related to patient health behaviors such as blood glucose monitoring, medication adherence, lifestyle changes, and physiological markers including body mass index, blood pressure, cholesterol level and glycemic control in patients with uncontrolled type 2 DM.	2008-2016	PICO (Participant-Intervention-Comparison-Outcomes) format, based on the Joanna Briggs Institute (JBI) (2014) [14], was used. Adults with uncontrolled type 2 DM, studies utilizing any treatment strategies (e.g., usual care, didactic method, participatory learning, internet-based methods) were included in this review	Excluded Studies: diabetes medication alone or intervention that did not include a family component, Non-RCTs or studies without control group, not published in an academic journal (e.g., unpublished dissertation), and studies focused on diabetes prevention	Total:23 RCTs:19 Non-RCTs with comparison:3 Observational:2	Hospital and home
	Kruse, 2015 ²⁴	Describe characteristics of portals associated with positive perception by patients and providers.	2004-2014	Attitudes of patients and providers re: patient portal.	Did not report patient & provider attitudes	Total:27 RCTs:0	Outpatient

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
Self-Management Support – Adults Only	Whitehead, 2016 ²⁵	To assess the effectiveness of mobile phone and tablet apps in self-management of key symptoms of long-term conditions. (Only one RCT from US)	2005-2016	Original research published in peer reviewed journals that evaluated self-management apps for their effect on disease-specific clinical outcomes such as HbA1C, BP, FEV1. RCTs with comparison or control group	(1) they reported on primary prevention among healthy or at-risk groups, (2) the focus lay outside of the self-management domain, (3) review papers, editorials, commentaries, (4) no chronic diseases (5) language other than English.	Total:9 RCTs:9 Non-RCTs with comparison:0 Observational:0	Home
	Kim, 2015 ²⁶	This systematic review is aimed at identifying the general characteristics of web-based self-management support interventions for cancer survivors and to perform the corresponding meta-analyses to assess the effects of these interventions	2000-2014	Patients diagnosed with cancer or their caregivers; Web-based self-management support interventions; behavioral or health outcomes; randomized controlled trials or quasi- experimental designs; Original research articles published in English in peer-reviewed journals between January 2000 and June 2014.	None listed	Total:37 RCTs:34 Non-RCTs with comparison:0 Observational:3	Setting not included

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Teljeur, 2016 ²⁷	To systematically review the evidence on the costs and cost-effectiveness of self-management support interventions for people with diabetes.	Not mentioned -2015	P: adults with Type I & II diabetes, I: substantial component of self management support, C: compared with routine care, O: costs and cost-effectiveness of self-management support interventions for people with diabetes. RCTs, observational studies or economic modelling studies were eligible for inclusion.	Part of the study population was from a nursing home or non-community dwelling setting; Excluded if only published as abstracts, people aged < 18 years; cost data were not clearly reported; or they compared blood glucose self-monitoring	Total:37 RCTs:6 Non-RCTs with comparison:11 Observational:20	Hospital and home
	Hecke, 2016 ²⁸	This SR aims to assess the quality of evidence and determine the effect of patient-related and economic outcomes of self-management support interventions in chronically ill patients with a low socio-economic status.	2000-2013	Patients age >18 yrs with chronic diseases having low SES, studies reporting on Self Management Support Interventions with a focus on patient-related outcomes and/or economic outcomes. No language restriction.	None listed	Total:27 RCTs:18 Non-RCTs with comparison:1 Observational:8	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Hooft, 2016 ²⁹	Realist Review: The aim of this study was to examine how nurse-led interventions that support self-management of outpatients with chronic conditions work and in what contexts they work successfully	2000-2015	Only studies using a comparison between 'standard care' and self-management support interventions (e.g. RCT, before–after design and qualitative and quantitative methods). Self-management support interventions with a prominent role for nurses, outpatient clinic setting, adults with chronic condition, evaluation study and written in the English language.	If results were not measured at a patient level, if the setting was a palliative care, primary care, or psychiatric care.	Total:38 RCTs:21 Non-RCTs with comparison:3 Observational:14	Hospital
	Stenberg, 2016 ³⁰	Scoping Review: To give a comprehensive overview of benefits and challenges from participating in group based patient education programs that are carried out by health care professionals and lay participants, aimed at promoting self-management for people living with chronic illness.	2008-2015	Articles in English and Scandinavian in peer-reviewed journals that had investigated the benefits and challenges from participating in patient education programs aimed at promoting self-management for people older than 18 years of age, living with chronic illness.	Studies excluded if lay participants were not involved in planning or carrying out the programs, not reporting on benefits or challenges from participation as reported by participants, and not chronic illness.	Total:47 RCTs:28 Non-RCTs with comparison:0 Observational:19	Hospital, home, community settings, CHCs

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Plow, 2016 ³¹	The purpose of this scoping review was to describe randomized controlled trials (RCTs) of tailored self-management interventions in adults with neurological and musculoskeletal conditions that characteristically result in mobility impairments. We focused on summarizing the outcomes of these RCTs and the strategies used to promote behavior change.	1980-2015	RCTs in English language with community-dwelling adults who acquire diseases or impairments in neurological or musculoskeletal systems and have an outcome measure of medication adherence, physical activity, nutrition, sleep hygiene, smoking cessation, or alcohol use.	(1) primarily evaluating the beneficial effects of exercise programs, medications, or vocational rehabilitation programs (2) including children or under 18 years old, adults living in a nursing home or receiving the entire intervention during inpatient care, older adults without needing to have a condition as defined above, and adults with a primary diagnosis of cardiovascular disease, epilepsy, cancer, endocrine disease, mental health disorder, or Alzheimer's disease (3) Studies on motivational interviewing (4) Conference proceedings, abstracts, and review articles	Total:13 RCTs:13 Non-RCTs with comparison:0 Observational:0	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Noonan, 2019 ³²	To quantify the impact of involving caregivers in self-management interventions on health-related quality of life of patients with heart failure or chronic obstructive pulmonary disease.	1990-2018	RCTs involving caregivers in self-management interventions (≥2 components) compared with usual care for adult patients with heart failure or chronic obstructive pulmonary disease. Primary outcome of analysis was patient health-related quality of life. Intervention: Self-management intervention programs which were comprised of two or more intervention components.	We excluded: (a) studies in long-term residential care setting; (b) studies where caregivers were not explicitly part of the intervention delivery.	Total:26 RCTs:26 Non-RCTs with comparison:0 Observational:0	Hospital and home
	Kuo, 2016 ³³	Assess the clinical evidence supporting the use of secure messaging in EHRs in self-management of diabetes.	Not mentioned- 2015	Patients with diabetes; secure messaging in EHR	No online secure messaging to communicate with providers	Total:11 RCTs:2 Non-RCTs with comparison:1 Observational:8	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Sakakibara, 2016 ³⁴	To describe the self management interventions used to improve risk factor control in stroke patients and quantitatively assess their effects overall risk factor control from lifestyle behavior and individual risk factors.	Inception-2015	RCTs were included if they involved a self-management intervention to improve risk factors in adults (aged 18 years and older) who have had a stroke or transient ischemic attack (TIA). Also active participation required. Clear definition of intervention and control treatments. English language.	Excluded if no comparison or if more than half of the study sample included individuals without a stroke diagnosis	Total:14 RCTs:14 Non-RCTs with comparison:0 Observational:0	Hospital and home
	Whiteman, 2016 ³⁵	Aimed to: review the evidence of the effect of self-management interventions targeting both medical and psychiatric illnesses and evaluate the potential for implementation.	1946-2015	P: Adults with a diagnosis of schizophrenia, schizoaffective disorder, or bipolar disorder and a chronic medical illness I: self-management intervention studies that address both medical and psychiatric self-management C: self-management skills and behaviors, self-management attitudes, biological outcomes, services utilization, and functional status. No restriction on language, and studies included randomized control trials, pre/post designs.	We excluded preventative interventions and health promotion or lifestyle interventions targeting substance use, smoking cessation, weight loss, weight-gain prevention, physical activity, or fitness.	Total:15 RCTs:9 Non-RCTs with comparison:6 Observational:0	Hospital and home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Sokol, 2016 ³⁶	To assess the reach and effectiveness of peer support among those who are hardly reached, along with peer support strategies (conceptual and operational) used.	2000-2015	Studies had to include prioritization of a hardly reached population, ongoing support from a nonprofessional, assistance in applying behavior change plans, and at least 1 of the 2 following components: social and emotional support or encouragement of recommended care.	Studies were excluded if they addressed temporally isolated behaviors rather than complex behaviors, were limited to protocol classes, were group taught or facilitated, included peer support as the dependent variable, did not include statistical tests of significance, or included comparison conditions that involved substantial social support.	Total:47 RCTs:13 Observational:34	Hospital, Community settings, CHCs
	Zomahoun, 2016 ³⁷	This SR aimed to assess whether Motivational Interview interventions are effective to enhance medication adherence in adults with chronic diseases and to explore the effect of individual MI intervention characteristics.	2012-2016	RCTs that assessed MI intervention effectiveness on medication adherence in adults with chronic diseases. Comparator groups had to include individuals who were not receiving MI. Outcomes: medication adherence had to be explicitly stated as the primary or secondary outcome of the MI intervention.	None listed	Total:19 RCTs:19 Non-RCTs with comparison:0 Observational:0	Hospital and home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Palacio, 2016 ³⁸	To evaluate the impact of motivational interviewing (MI) and of the MI delivery format, fidelity assessment, fidelity-based feedback, counselors' background and MI exposure time on adherence.	1966-2015	Randomized trials that compared MI to one or more control groups, reported a measure of medication adherence in numerical form, had a follow-up period of any length and were published in English.	Studies that used MI in combination with other strategies since the isolated effect of MI could not be determined, were excluded.	Total:17 RCTs:17 Non-RCTs with comparison:0 Observational:0	Hospital
	Eeden, 2016 ³⁹	Objective was to systematically review the literature of full economic evaluation studies of self-management interventions in adult chronic patients and to investigate their methodological quality and cost-effectiveness.	1990-2014	Full economic evaluation studies reporting on SMI in line with Barlow's definition (2) of self-management of chronic diseases were eligible for inclusion.	Studies were Excluded if patients could not be classified as having a chronic disease or receiving chronic care, if participants were younger than 18 years of age, if the study was not written in English or Dutch and/or was published before 1990.	Total:22 RCTs:6 Non-RCTs with comparison:13 Observational:3	Hospital and home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Jacelon, 2016 ⁴⁰	The purpose of this scoping review of literature is to explore the types of computer-based systems used for self-management of chronic disease, the goals and success of these systems, the value added by technology integration and the target audience for these systems.	2006-2016	The research articles included were focused on technology for self-management of chronic disease.	Excluded if they were not focused on self-management, were not primary research, were not technology-based or were integrative reviews; they were also excluded if the intervention provided feedback only to the clinician and not to the person with the disease	Total:30	Hospital and home
	Smith, 2017 ⁴¹	This review aimed to identify and summarize the existing evidence on the effectiveness of interventions to improve clinical and mental health outcomes and patient-reported outcomes including health-related quality of life for people with multi-morbidity in primary care and community settings.	1990-2015	P: Any people or populations with multi-morbidity receiving care in a primary or community care setting only. I: any type of intervention that was specifically directed towards a group of people defined as having multi-morbidity. O: clinical or mental health outcomes (e.g. blood pressure, symptom scores, depression scores), Patient-reported outcome measures (e.g. quality of life, well-being, measures of disability or functional status), Utilization of health services	Studies where interventions were directed at communities of people based on location or age of participants in which participants could be presumed to have multimorbidity on the basis of their age or residence in a nursing home but interventions were not designed to specifically target multimorbidity.	Total:18 RCTs:18 Non-RCTs with comparison:0 Observational:0	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Hammer, 2015 ⁴²	The purpose of this integrative review is to evaluate intervention studies led by nurse principal investigators for self-care management in patients with cancer	2000-2012	Adults/older adults with cancer who received an intervention to help with self-management from disease and treatment-related effects, with comparison to same patient populations receiving usual care, and through an experimental design study	Studies that addressed the following areas without also containing a self-care intervention: medications, surgical procedures, treatment decision making, perception, needs assessment, evaluations of patient-provider communication, evaluations of screenings, evaluation of barriers to symptom management, validation of assessment questionnaires. Non-English articles were also excluded.	Total:46 RCTs:35 Non-RCTs with comparison:0 Observational:11	Outpatient clinics, home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Kim, 2016 ⁴³	A systematic review to synthesize evidence concerning the types of CBHW interventions, the qualification and characteristics of CBHWs, and patient outcomes and cost-effectiveness of such interventions in vulnerable populations with chronic, non-communicable conditions	Not mentioned-2014	(1) Randomized controlled trials published in English in peer-reviewed journals, (2) studies testing CBHW-led interventions, (3) studies focused on adults, and (4) studies focused on chronic conditions.	(1) Studies focused on children, (2) non-data-based articles (e.g., editorials, commentaries), and (3) studies focused on non-vulnerable populations.	Total:67 RCTs:67 Non-RCTs with comparison:0 Observational:0	Home, hospital/clinic/CHC, community centers, churches
	Thakkar, 2016 ⁴⁴	To conduct a meta-analysis of randomized clinical trials to assess the effect of mobile telephone text messaging on medication adherence in chronic disease.	Inception-2015	(1) The trial studied adult patients (≥18 years) with chronic disease, (2) the patients received a mobile telephone text message intervention designed to promote medication adherence, (3) the design was a randomized clinical trial (RCT) with at least 4 weeks' follow-up, and (4) the trial reported quantitative measures of the effect of text messaging on medication adherence	(1) primary intervention under consideration was not limited to text messages, (2) the focus was solely disease management or education and did not report medication adherence or reported only surrogate outcomes (3) the study involved psychiatric, military, or institutionalized patients.	Total:16 RCTs:0 Non-RCTs with comparison:0 Observational:0	Inpatient, outpatient clinics

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Deek, 2016 ⁴⁵	To identify elements of effective family-centered self-care interventions that are likely to improve outcomes of adults living with chronic conditions	2000-2014	Quantitative studies targeting patient outcomes through family- centered interventions in adults with chronic disease	Studies were excluded if they were not intervention studies, caregiver-focused outcome interventions, had no family involvement, centered on pediatric and adolescent populations, review papers, pilot studies, protocols or concerned non-chronic conditions	Total:10 RCTs:9 Non-RCTs with comparison:1 Observational:0	Hospital and home
	Bolscher-Niehuis, 2016 ⁴⁶	To gain insight into the evidence of the effects of self-management support programs on the activities of daily living of older adults living at home.	1998-2015	Studies that described a self-management support program directed at adults of on average 65 years or older, and living in the community, used RCT design and presented information about the effects on activities of daily living.	None listed	Total:12 RCTs:12 Non-RCTs with comparison:0 Observational:0	Hospital

	Alessa, 2018 ⁴⁷	A systematic review was conducted to assess the effectiveness of apps in lowering blood pressure, as well as their usability and patients' satisfaction with their use.	2008-2016	The population was people with hypertension (18 years of age and over) and health care professionals (HCPs) supporting people with hypertension in their self-management in any care setting; The intervention was a mobile phone or a tablet app that collects data, provides feedback, connects with HCPs or informs about hypertension to support the self-management tasks of hypertension; The comparator was either usual care or any other control intervention. Articles with no comparison were also included; The eligible study designs were all quantitative, qualitative, and mixed-method studies that explore the self-management of hypertension using apps	1. not aimed at hypertension or studies focusing only on primary prevention of hypertension. 2. They examined interventions accessed by a personal digital assistant, desktop computer, laptop, netbook 3. examined interventions accessed by a mobile phone or traditional tablet that did not permit participants to download or use any app from the app store. 4. solely used messaging including text messaging, multimedia messaging service (MMS), websites, calls, emails or Web-based apps. 5. A mobile device was used to transmit information provided by a blood pressure monitoring device, but in which there was no interaction with the user. 6. They describe only the technological development	Total:21 RCTs:9 Non-RCTs with comparison:10 Observational:2	Home
	Debon, 2019 ⁴⁸	To identify mobile health applications	Inception-2018	Studies that mentioned the use of mobile	None listed	Total:24	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
		with features for improving the lifestyle of patients with chronic diseases.		APPs allowing user interaction or testing for the change in lifestyle of patients with chronic disease and addressed at least one routine or treatment task for monitoring chronic diseases.		RCTs:0	
	Luedke, 2019 ⁴⁹	For adults with epilepsy, i. What are the most commonly employed components of self-management interventions evaluated in comparative studies? li. Effects of self-management interventions on self-management skills and self-efficacy, clinical outcomes, and health care utilization iii. Barriers and facilitators	Inception-2018	Randomized or quasi-experimental studies that enrolled adults with epilepsy, evaluated self-management interventions, and reported a relevant clinical, process, or economic outcome. Plus additional observational designs and qualitative studies addressing facilitators or barriers to adoption or implementation.	None listed	Total:28 RCTs:13 Non-RCTs with comparison:2 Observational:13	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Warner, 2019 ⁵⁰	To identify whether community-based Self-Management Programs (SMPs) actively engaged, or taught, individuals patient-oriented strategies; and whether having these attributes led to significant differences in outcomes.	1986-2016	adults 65 years of age and older (of any ethnicity) who had one or more chronic conditions, I: Community-based Self Management Programs, C: usual care or an attention control condition (e.g. equivalent time engagement but without an intervention), O: patient-oriented self-management strategies, Studies: RCTs, C-RCT	Chronic conditions that were not relevant to older adults or had minimal impact on everyday life. Trials in which the participants' age could not be assessed from the report or after contacting the authors, or where the mean age of participants in the trial was less than 65 years. Programs directed at clinicians or caregivers.	Total:31 RCTs:31 Non-RCTs with comparison:0 Observational:0	Community settings or CHCs
	Han, 2019 ⁵¹	Effects of community health center interventions in people with diabetes	Inception-2018	Articles were included in this review if the study was: about diabetes mellitus, published in the English language and involved participants who were 18 years and older. Additionally, only intervention studies that were conducted within a CHC setting in the U.S., and studies that reported patient outcomes were included	None listed	Total:29 RCTs:17 Non-RCTs with comparison:2 Observational:8	Outpatient clinic

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Levengood, 2019 ⁵²	Examine the effectiveness of team based care in improving health outcomes of people living with diabetes	2003-2015	Studies were included if the following criteria were met: focused on people diagnosed with Type 1 or 2 diabetes; conducted in a World Bank–designated high-income economy ¹⁰ and published in English; RCT; team consisted of patient, primary care provider (not necessarily a physician), and one or more healthcare professionals; team members aware of each other's roles and responsibilities; relied on multidirectional flow of information to manage patient care; care was ongoing, longitudinal (two or more contacts between patients and added team members); and included one or more outcomes of interest	None listed	Total:35 RCTs:35 Non-RCTs with comparison:0 Observational:0	Hospital, outpatient clinic, home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Zhao, 2015 ⁵³	To examine the effectiveness of telemedicine in relieving asthma symptoms.	Inception-2013	P: Adults 18 years of age with Asthma, I: intervention involved any format of telemedicine such as text messaging, telephone, Internet, or mobile phone, C: usual care, O: clinical outcome of controlling asthma symptoms, Study design: randomized controlled trials	Exclusion criteria were as follows: (1) participants had a diagnosis of a lung disease other than asthma; (2) the study did not evaluate changes of asthma symptoms; (3) non-English publication; and (4) the publication was a letter, comment, editorial, or case report	Total:11 RCTs:11 Non-RCTs with comparison:0 Observational:0	Hospital and home
	Lederle, 2019 ⁵⁴	Our review and meta-analysis sheds light on the relationship between lay-led self-management programs and health care utilization.	2006-2017	Lay-led strategies for self-management, 1 or more chronic disease, health care utilization outcomes, in person component	Children and adolescents	Total:49 RCTs:33 Non-RCTs with comparison:0 Observational:16	Outpatient clinic
	Nazarov, 2019 ⁵⁵	Identify studies of interventions that support the maintenance of work and return to work (RTW) among workers with chronic illnesses.	Not mentioned-2018	RCTs and controlled clinical trials (CCTs) were included. Studies were selected if they described factors related to RTW of employed adults (aged 18+) with chronic disease	Any other study form without a comparison group	Total:15 RCTs:15 Non-RCTs with comparison:0 Observational:0	Workplace

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Sangrar, 2019 ⁵⁶	To review the literature on chronic disease self-management programs that blend face-to-face and online/computer-based education design and delivery.	2004-2019	Included studies where participants had cancer, cardiovascular disease and/or mental illnesses in addition to the chronic diseases of interest; Only patient education programs that combined face-to-face and online/computer-based strategies delivered or mediated by healthcare professionals in at least one study arm were included	We excluded studies focused only on patients with cancers, cardiovascular conditions, and serious mental illnesses	Total:12 RCTs:6 Non-RCTs with comparison:1 Observational:5	Outpatient Clinic, home
	Zhao, 2016 ⁵⁷	To synthesize the effects of theory-based self-management educational interventions on patients with type 2 diabetes (T2DM) in randomized controlled trials.	1980-2015	Population: targeted participants ≥18 years old and with T2DM. I: educational intervention was based on a theory/model, with a clear description in the study, or used a structured method which had a theory as the background, C: compared with routine care. O: HbA1c and BMI, Self efficacy. Studies: RCTs	Studies including children, no comparison or non-RCTs	Total:20 RCTs:20 Non-RCTs with comparison:0 Observational:0	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Skrabal Ross, 2018 ⁵⁸	aims to explore what is known about mobile phone–delivered interventions designed to enhance adherence to oral chemotherapy, to examine the reported findings on the utility of these interventions in increasing oral chemotherapy adherence, and to identify opportunities for development of future interventions	Not mentioned-2018	(1) research-based studies on interventions that aim to increase adherence to oral chemotherapy or endocrine therapy, (2) targets cancer patients taking oral chemotherapy or endocrine therapy, (3) use of mobile phones as a main tool to deliver the intervention, and (4) articles written in English.	None listed	Total:5 RCTs:2 Non-RCTs with comparison:0 Observational:3	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Ha Dinh, 2016 ⁵⁹	This systematic review examined the evidence on using the teach-back method in health education programs for improving adherence and self-management of people with chronic disease	Inception-2013	Adult patients (aged 18 years and over) in any healthcare setting with one or more chronic disease including heart failure, diabetes, cardiovascular disease, cancer, asthma, chronic obstructive pulmonary disease, chronic kidney disease, arthritis, epilepsy or a mental health condition; Eligible studies were those which reported on the use of the teach-back method alone or in combination with other supporting educational strategies; This review considered quantitative studies including randomized controlled trials (RCTs), non-randomized controlled trials, quasi-experimental studies, case-controlled studies, cohort studies, and before and after studies; Studies published in English were considered for inclusion in this review.	Studies that included seriously ill patients, and/or those with impairments in verbal communication and cognitive function were excluded.	Total:10 RCTs:8 Non-RCTs with comparison:1 Observational:1	Inpatient, outpatient clinics, home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Ko, 2018 ⁶⁰	This review aimed to examine how self-management has been operationalized in the context of multiple chronic conditions.	2006-2017	Peer-reviewed research articles which operationalized self-management in adults with at least two or more chronic illnesses in adults > 18 Y were selected.	Articles were excluded if they used instruments that operationalized self-management for specific single chronic illness populations such as diabetes or heart failure.	Total:7 RCTs:4 Non-RCTs with comparison:0 Observational:3	Hospital and home
	Changizi, 2017 ⁶¹	The present study was conducted aiming to assess the effectiveness of mHealth in improving health behaviors among an elderly population	2012-2016	Use of mHealth for promoting health behavior in elderly populations (age of 60 and over), with a main focus on authentic experiments and clinical trials	Irrelevance to the main subject, younger age-group, methodology, study design (review article, descriptive, cross-sectional study, survey research) and lack of originality	Total:12 RCTs:10 Non-RCTs with comparison:0 Observational:2	Home, outpatient clinic

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Kelly, 2018 ⁶²	To assess the efficacy, cost-effectiveness and adverse effects of self-management interventions for adults and children with non-cystic fibrosis bronchiectasis.	1937-2018	Randomized controlled trials of any duration that included adults or children with a diagnosis of non-cystic fibrosis bronchiectasis assessing self-management interventions delivered in any form. Self-management interventions included at least two of the following elements: patient education, airway clearance techniques, adherence to medication, exercise (including pulmonary rehabilitation) and action plans.	We excluded participants with a diagnosis of cystic fibrosis (CF), sarcoidosis or active allergic bronchopulmonary aspergillosis. We also excluded studies of other long-term health conditions unless results for people with bronchiectasis were reported s	Total:2 RCTs:2 Non-RCTs with comparison:0 Observational:0	Home, outpatient clinic

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Jeddi, 2017 ⁶³	We conducted a systematic review of randomized controlled trials (RCTs) to assess the features and effects of IT-based interventions on self-management outcomes of CKD patients	Not mentioned- 2016	(1) IT-based interventions in patients with CKD stages 1 to 5; (2) Interventions with all kinds of IT-based tools, such as a smart phone, tablet, smart TV or computer, that support all or part of the intervention consisting of the self-management; (3) The study design being a randomized controlled trial (RCT); (4) Having a control group receiving standard/ usual care without IT-based systems.	(1) Studies in which healthcare providers were the consumers of the intervention; (2) Studies with the IT-based intervention performed only through the direct involvement of healthcare providers; (3) Studies focused on the feasibility, validity, acceptability, or description of IT-based tools and systems; (4) Descriptive studies without comparison group, case reports, commentaries, reviews, study protocols, surveys, conference proceedings, and before-after trials.	Total:8 RCTs:8 Non-RCTs with comparison:0 Observational:0	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Conway, 2017 ⁶⁴	The objective of this integrative review was to examine the types of digital health technologies that targeted medication adherence in the adult population with diabetes or hypertension	2006-2016	(1) English-language, peer-reviewed randomized controlled trials (RCTs) with quasi-experimental, observational, or qualitative design; (2) studies containing digital health interventions to improve medication adherence to prescription medications in adults (ie, 18 years or older); and (3) studies focused on diabetes or hypertension.	(1) studies that did not include results of medication adherence rates or (2) pilot studies	Total:13 RCTs:9 Non-RCTs with comparison:0 Observational:4	Home
	Kim, 2017 ⁶⁵	Scoping review to (1) understand the nature, extent, and range of smart device-based research activities, (2) identify the limitations of the current research and knowledge gap, (3) recommend future research directions	2010-2016	All study designs, only articles published in 2010 or after were selected to accommodate the introduction of tablets and the wide adoption of smartphones, average age of participants was 50 years or older, aimed to support chronic disease management.	SMS or interactive voice response-based mHealth interventions, (2) studies that validated electronic versions of scales or questionnaire forms of existing instruments, (3) smart device-based interventions for postoperative monitoring	Total:51 RCTs:13 Non-RCTs with comparison:5 Observational:33	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Cho, 2017 ⁶⁶	SR: Aim of this SR was to assess the impact of technology-mediated interventions on QoL and to identify the instruments used to measure the QoL of persons living with HIV/AIDS (PLWH).	1994-2016	1) manuscript; 2) RCTs that assessed the impact of technology-mediated interventions as compared to usual care or any other intervention; 3) population of interest as PLWH; 4) examined QoL as a health outcome.	Excluded poster sessions, presentations, protocols, letters, comments, editorials, correspondences or grey literature (e.g., blogs, newsletters, videos).	Total:10 RCTs:10 Non-RCTs with comparison:0 Observational:0	Hospital and home
	Clarkesmith, 2017 ⁶⁷	SR: Synthesizing the evidence about the effects of educational and behavioral interventions in patients with atrial fibrillation who are taking oral anticoagulant medication.	1806-2016	Randomized controlled trials (RCTs) of educational or behavioral interventions with any length of follow-up and in any language included. Adults (aged 18 years or older) with AF, categorized according to the European Society of Cardiology (ESC) guidelines. Interventions and outcomes as mentioned.	None listed	Total:11 RCTs:10 Non-RCTs with comparison:0 Observational:0	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Massimi, 2017 ⁶⁸	The aim of this systematic review and meta-analysis is to assess the efficacy of the nurse-led self-management support versus usual care evaluating patient outcomes in chronic care community programs.	1990-2016	"P: adults 65 years of age and older (of any ethnicity) who had one or more chronic conditions, I: nurse-led self-management support intervention, C: compared to the usual care, to improve O: observer-reported outcomes (OROs) particularly clinical outcomes and patient-reported outcomes (PROs). Studies design: RCTs"	In-hospital based care and discharge planning program from hospital were excluded. Non RCT design or without comparison excluded	Total:29 RCTs:13	Patient home and community based facilities
	Dounavi, 2019 ⁶⁹	Identify existing evidence on the efficacy of mobile health technology in facilitating weight management behaviors, such as healthy food consumption and physical activity	2012-2017	(1) adult population; (2) typical intellectual ability; (3) dependent variable: weight management behaviors; (4) independent variable: use of mobile technology including self-monitoring strategies; and (5) primary study	(1) age <18 years; (2) diagnosis of intellectual disability; (3) weight gain control in pregnancy or postpartum weight loss; (4) use of mobile technology for education/provision of information versus interactive use for self-management	Total:39 RCTs:22 Non-RCTs with comparison:2 Observational:15	Outpatient Clinic, home
	Price, 2015 ⁷⁰	Describe evidence for benefit from patient health record-enabled management, by health condition.	2008-2014	Intervention =self-care activities; Use pf PHR; Outpatient	Patients not using PHR; usability testing	Total:23 RCTs:7 Non-RCTs with comparison:2 Observational:14	Outpatient

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Aquino, 2017 ⁷¹	To identify and evaluate the effectiveness of individual empowerment strategies inpatients with diabetes mellitus (DM).	Not mentioned- 2016	“P” (problem): patients with diabetes mellitus; “I” (intervention): individual intervention strategies for empowerment; “C” (control): patients without intervention for empowerment; “O” (outcomes): reduction of HbA1c; “S” (study design): randomized controlled trials.	Review articles, editorials, letters to the editor, news reports, comments, as well as the results of dissertations, theses or abstracts published in annals of congress or scientific journals, articles with collective strategies or using both strategies	Total:11 RCTs:11 Non-RCTs with comparison:0 Observational:0	Hospital and home
	Ammenwerth, 2019 ⁷²	Assess the effect of patient portals on patient empowerment and health-related outcomes.	2000-2017	Applied patient portal taxonomy - access, remind, request, communicate, share, manage, educate.	Exclude age <18 or wen caregivers were targeted	Total:10 RCTs:10 Non-RCTs with comparison:0 Observational:0	Outpatient
	Donald, 2018 ⁷³	To systematically identify and describe self management interventions for adult patients with chronic kidney disease (CKD).	Not mentioned- 2016	All studies included (RCTs, Non RCTs, Quasi, Prepost, Obs), self management interventions for adult patients with chronic kidney disease (CKD). Outcomes included behaviors, cognitions, physiological measures, symptoms, health status and healthcare.		Total:50 RCTs:19 Non-RCTs with comparison:13	Community-based

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Boulley, 2018 ⁷⁴	This study aims to highlight the components of Digital health interventions (DI), investigate patient engagement with DI, and explore the effects of DI on psychosocial variables.	Inception-2017	(1) reviewed and published in English, (2) tested one or more DI, (3) assessed psychosocial variables or engagement with DI, (4) presented DI focused on helping patients or survivors to autonomously manage their health condition on a daily basis (5) presented a main study, a pilot study, or an exploratory study, and, (6) presented a study which had one of the following design types: RCT, cross-sectional study or pretest-posttest study.	Studies were excluded when (1) the DI presented aimed at preventing or detecting cancer, (2) participants did not actually use D-tools, (3) psychosocial variables, or engagement with DI were not assessed, (4) the DI presented aimed at improving self-care	Total:29 RCTs:15 Non-RCTs with comparison:8 Observational:6	Hospital and home
	Peytremann-Bridevaux, 2015 ⁷⁵	To evaluate the effectiveness of chronic disease management programs for adults with asthma.	Inception-2014	We included individual or cluster-randomized controlled trials, non-randomized controlled trials, and controlled before-after studies comparing chronic disease management programs with usual care in adults over 16 years of age with a diagnosis of asthma	We excluded studies in which patients with other significant pulmonary chronic disease (like moderate or severe COPD or bronchiectasis) represented a significant proportion of participants, unless subgroup analysis was available.	Total:20 RCTs:15 Non-RCTs with comparison:5 Observational:0	Inpatient, outpatient clinics

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Laukner, 2016 ⁷⁶	A scoping review was undertaken to discover community-based peer support initiatives for adults in rural settings living with chronic conditions	2000-2014	Interventions/programs (rather than opinion pieces); the years 2000–January 2014 (to ensure currency); English only (due to language limitations of the research group); adults (≥18 years); explicit involvement of peers who work with people who have a chronic condition the peer is familiar with; community-based (rather than hospital-based) with an emphasis on community involvement (rather than medical management); explicit reference to being located in rural settings.	professional-led initiatives with no focus on the development of peer supports; initiatives that only focus on friendship development without reference to community involvement; initiatives that focus on caregivers of people with chronic conditions	Total:13	Outpatient Clinics, home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Lee, 2018 ⁷⁷	We conducted a systematic review to examine the effectiveness of mHealth interventions on process measures as well as health outcomes in randomized controlled trials (RCTs) to improve chronic disease management.	2005-2016	The inclusion criteria were RCTs that conducted an intervention using mobile devices such as smartphones or tablets for adult patients with chronic diseases to examine disease management or health promotion.	The exclusion criteria were as follows: studies that focused on a healthy population, pregnant women, non-adults (i.e., adolescents and children), or healthcare providers (e.g., apps, for physicians' or nurses' use only); studies that used only qualitative methods	Total:12 RCTs:12 Non-RCTs with comparison:0 Observational:0	Hospital and home
	Warrington, 2019 ⁷⁸	This review aimed to (1) describe the features and functions of existing electronic symptom reporting systems (eg, symptom monitoring, tailored self-management advice), and (2) explore which features may be associated with patient engagement and patient-centered outcomes.	2000-2016	"P: Male and female adults >18, I: Online systems for patients to report or manage symptoms and side effects during cancer treatment from home; Internet-based or -enabled systems, including mobile apps. C: Stage 2 only: The review included studies with any comparator and non comparator, O: Monitoring of symptoms by health care professionals (HCPs) and patients, QoL measures; self-efficacy measures including patient activation, patient empowerment, mastery; and patient satisfaction."	Systems designed to be accessed at one time point only were excluded; access to the system had to be ongoing.	Total:29 RCTs:7 Non-RCTs with comparison:1 Observational:21	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Palacios, 2017 ⁷⁹	To conduct a systematic review to (1) determine the effectiveness of Internet-delivered CHD self-management support for improving CHD, mood, and self-management related outcomes and (2) identify and describe essential components for effectiveness. (Note: only one study from the US out of seven RCTs included in this review)	2000-2015	Studies with following format. P: Adults with a diagnosis (clinician or self-reported) of CHD, I: Tested the effectiveness of Internet-delivered self management support for CHD and addressed wellbeing outcomes, such as mood, quality of life, or functional status. C: comparison groups: usual care, waiting list, attention, information, or online discussion group O: Clinical outcomes, lifestyles changes, QoL, mental health.	Studies not in English and without RCT design or comparison excluded	Total:7 RCTs:7 Non-RCTs with comparison:0 Observational:0	Home
	Warner, 2015 ⁸⁰	SR to identify self-management support strategies in stroke self management interventions and effectively improved outcomes, focusing specifically on function and participation outcomes.	1986-2012	Pre-post, quasi-experimental and randomized controlled trial study designs with comparison group/usual care, self-management support strategies in stroke patients, were included	Excluded if they only disseminated information (e.g. self-help workbooks, provision of written materials, tapes or DVDs) or reported on a single intervention strategy [cognitive behavioral therapy (CBT), exercise, self-help group, relaxation, information]	Total:95 RCTs:6 Non-RCTs with comparison:3 Observational:86	Hospital, CHC

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Dendere, 2019 ⁸¹	Assess effect of inpatient patient portals on patient engagement, health care delivery	2005-2017	Hospital, inpatient; hospital EMR with patient portal	None listed	Total:58	Hospital
	Almutairi, 2019 ⁸²	To assess the effectiveness of patient activation intervention on T2DM glycemic control and Self-management behaviors SMBs.	2004-2018	We included randomized controlled trials with sample size ≥ 120 and follow up period of ≥ 12 months and assess the effectiveness of patient activation intervention on T2DM glycemic control and SMBs	Excluded if the intervention was not based on patient activation, the participants were less than 18 years of age, had other types of diabetes, the outcomes were not self-management behavior and glycemic control, the design was not RCT, sample size was less than 120, and lastly, the duration of follow-up was less than 12 months	Total:10 RCTs:10 Non-RCTs with comparison:0 Observational:0	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Kelly, 2018 ⁸³	Review the literature evaluating the design, use, and impact of inpatient portals, which are patient portals designed to give hospitalized patients and caregivers inpatient EHR clinical information for the purpose of engaging them in hospital care.	2006-2017	Hospital EMR	Exclude of only ER or ambulatory portal.	Total:9 RCTs:0 Non-RCTs with comparison:1 Observational:8	Hospital
	Risling, 2017 ⁸⁴	explore the concept of patient empowerment within the electronic health (eHealth) context	2000-2016	EHR, PHR or patient portal	not on EHR	Total:19 RCTs:1 Non-RCTs with comparison:2 Observational:16	Outpatient

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Hamine, 2015 ⁸⁵	We conducted a systematic review of the literature to evaluate the effectiveness of mHealth in supporting the adherence of patients to chronic diseases management (“mAdherence”), and the usability, feasibility, and acceptability of mAdherence tools and platforms in chronic disease management among patients and health care providers.	1980-2014	We included original research published in peer-reviewed journals that evaluated mHealth tools for effect on patient adherence to chronic disease management, disease-specific clinical outcomes, and usability, feasibility, and acceptability features. Studies that focused on clinical measures, such as hemoglobin A1c (HbA1c) or blood pressure (BP), were included; Only articles reporting that the mAdherence intervention was designed for secondary prevention targeting chronic disease patients were included	Studies on primary prevention among healthy or at-risk groups. We also excluded articles regarding interventions that were not tested in a sample population with clearly described methods and results. In addition, review articles, editorials, commentaries	Total:107 RCTs:50 Non-RCTs with comparison:17 Observational:40	Setting not included

	Wildevuur, 2015 ⁸⁶	(1) which ICT interventions have been used to support patients and health care professionals in PCC management of the big 5 chronic diseases? and (2) what is the impact of these interventions, such as on health-related quality of life and cost efficiency?	1989-2013	1989-2013; Publications in English language; Persons coping with one or more of the "big five" of chronic diseases; Chronic Care for persons already diagnosed with a chronic disease; Person centered self management and self care involved ICT involved; Medical study relating outcomes to ICT-intervention; Theoretical study outcomes such as frameworks; Study outcomes measuring Health related quality of life (HRQL) and Quality of Life (QoL); Study outcomes measuring Cost efficiency; study outcomes measuring other impact and performance factors; Documenting, monitoring and interaction applications for person-centered care; Connected care communication: multiple target groups as users of the application; Related to a person or patient; Minimal two users involved; a patient person with chronic condition and health care professional; Home health care	Publications before 1989; Publications in other languages than English; Letters, editorials, news items and conference abstracts; Persons coping with an acute diseases, such as acute stroke Preventive Care and Public Care involving screening and prevention	Total:350	Home
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Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
				setting: care activities at home connected to care activities at other health care settings			

	Jones, 2015 ⁸⁷	The purpose of this review is to evaluate the efficacy of self-management programs in increasing physical activity levels in adults living in the community following acquired brain injury	Inception-2014	Randomized controlled trial (RCT); Quasi-randomized controlled trial (QRCT) - for example, allocation by date of birth, location, medical record number; Adults (18 years and over); Non-degenerative acquired brain injury (ABI); Currently living in the community; Are not undergoing significant medical or surgical intervention; Self-management program which: Includes at least one of the following components: problem-solving, goal-setting, decision-making, self-monitoring, coping strategies, or another approach to facilitate behavior change; Has at least a component of the program focusing on increasing physical activity. Must include at least one of the following: A measure of physical activity: either from a physical activity monitoring device (for example, accelerometer, pedometer) or a self-report measure; And/or A study outcome associated specifically with physical activity, for example, physical activity self-efficacy,	Studies examining individuals with degenerative ABI (for example Parkinson's disease or multiple sclerosis), cerebral palsy, developmental delay, fetal alcohol spectrum disorder (FASD), concussion, or transient ischemic attacks (TIA) were not included	Total:5 RCTs:5 Non-RCTs with comparison:0 Observational:0	Outpatient Clinics, home
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Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
				physical self-concept, or stages of change in relation to physical activity.			
	Pereira, 2015 ⁸⁸	The purpose of this article is to review various delivery methods of Internet diabetes education that have been evaluated, as well as their effectiveness in improving diabetes-related outcomes. (Diabetes self-management education)	2004-2013	Publications in English, type 2 diabetes education interventions (including those focused on health maintenance and prevention of complications), adult participants (age 18 years or older), and specifically programs offered via the Internet. Randomized trials, exploratory studies, and comparative effectiveness designs were included.	Healthcare provider education programs, face-to-face or non-Internet-based diabetes education interventions, studies focused on multiple diseases or other types of diabetes, pediatric samples (age < 18 years), and studies focused on primary outcomes relate	Total:14 RCTs:9 Non-RCTs with comparison:1 Observational:4	Hospital and home
	Kruse, 2015 ⁸⁹	Describe effect of patient portals on quality of care and chronic disease outcomes	2011-2014	All study designs included	Did not report portal.	Total:27	Outpatient
	Yin, 2019 ⁹⁰	How mobile health apps for IBD care have fit into a clinical care framework and the challenges that clinicians and technologists face in approaching future opportunities.	2010-2019	Articles exploring the use of a digital health intervention in the care of IBD, or CD or UC specifically.	Excluded if they did not involve IBD, CD, or UC or teleconferencing or video chatting as the sole intervention.	Total:28 RCTs:14	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
Shared Decision Making – Children Only	Malone, 2019 ⁹¹	To assess the effectiveness of interventions that promote participation in shared decision-making for children and adolescents (aged between four and 18 years) with CF.	Inception-2019	Randomized controlled trials (RCTs) (but not cross-over RCTs) of interventions promoting shared decision-making for children and adolescents with CF aged between four and 18 years, such as information provision, booklets, two-way interaction, checking understanding (by the participant), preparation to participate in a healthcare decision, decision-aids, and training interventions or educational programs. We planned to include interventions aimed at children or adolescents (or both), parents or healthcare professionals or any combination of these groups provided that the focus was aimed at promoting shared decision-making for children and adolescents with CF	None listed	Total:0 RCTs:0 Non-RCTs with comparison:0 Observational:0	

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Cheng, 2017 ⁹²	The aim of this scoping review was to identify and describe SDM approaches (tools, techniques, and technologies) used in child and youth mental health	Inception-2016	English language; described an SDM approach (tool, technique, or technology); included sufficient detail on the SDM approach for quality assessment; did not use only a questionnaire to provide feedback on SDM or related concepts (e.g., therapeutic alliance) without another SDM approach; child or adolescent population (up to 18 years); carers of children or adolescents; and mental health setting	Did not describe an SDM approach but merely used the term “SDM” in the record; adult population not in the context of caring for children or adolescents; and were not based in mental health services or settings	Total:15 RCTs:4 Non-RCTs with comparison:0 Observational:11	Clinics
	Coyne, 2016 ⁹³	To examine the effects of SDM interventions on the process of SDM for children with cancer who are aged four to 18 years.	Inception-2016	Randomized controlled trials (RCTs) and controlled clinical trials (CCTs) of SDM interventions for children with cancer aged four to 18 years. The types of decisions included were: treatment, health care and research participation decisions.	None listed	Total:0 RCTs:0 Non-RCTs with comparison:0 Observational:0	

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Wyatt, 2015 ⁹⁴	To summarize the efficacy of SDM interventions in pediatrics on patient-centered outcomes.	Inception-2013	We broadly defined SDM as the process of involving patients or their caregivers/surrogates in medical decision making with clinicians. As such, methods or approaches (including tools) designed to facilitate involvement in the process of medical decision making involving patients <18 years of age, their parents, or both and reported in English were eligible for inclusion	We excluded studies on antenatal/perinatal care and research participation decisions	Total:6 RCTs:4 Non-RCTs with comparison:1 Observational:1	Clinics

Shared Decision Making – Adults and Children	Voruganti, 2017 ⁹⁵	(1) Conduct a systematic search of the published literature and the Internet for Web-based tools for text-based communication between patients and providers; (2) map tool characteristics, their intended use, contexts in which they were used, and by whom; (3) describe the nature of their evaluation; and (4) understand the terminology used to describe the tools.	Not mentioned- 2016	Supports Web-based communication between patients and health professionals for within-tool communication (ie, messages sent within the tool are responded to using the tool rather than via phone call outside the tool environment); Uses a text-based form of dialogue (including text messages via cell phone); one or more chronic conditions, used in the health care context; Is intended for patients and health care providers (physician, nurse, pharmacist, social worker, etc) to communicate regarding direct patient care; Communication may be guided but not restricted (ie, patient should have the opportunity to ask any question); Involves communication between a minimum of one patient and one health care professional (ie, at least two end users	Tools that function for information transfer but not communication <ul style="list-style-type: none"> • Audio or video-based forms of communication that do not include text-based communication • Electronic medical records, patient health data repositories, and portals that do not have a communication component • Online support forums, even if they support communication between many patients and many health professionals • Tools for communication exclusively between patients • Theoretical or conceptual papers, frameworks, and descriptions • Offline native apps for mobile devices (ie, those which are not connected to the Internet) • Tools to support behavior change interventions in otherwise healthy patients (ie, without 	Total:54 RCTs:25 Non-RCTs with comparison:23 Observational:6	Home
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Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
					a chronic condition; eg, smoking cessation, diet, and alcoholism)		
	Kew, 2017 ⁹⁶	To assess benefits and potential harms of shared decision-making for adults and children with asthma.	Not mentioned-2016	We included studies of individual or cluster parallel randomized controlled design conducted to compare an SDM intervention for adults and children with asthma versus a control intervention. No restrictions on place, date, or language of publication. Interventions targeting healthcare professionals or patients, their families or care-givers, or both.	We excluded studies of interventions that involved multiple components other than the SDM intervention unless the control group also received these interventions.	Total:4 RCTs:4 Non-RCTs with comparison:0 Observational:0	Hospital and home
	Clayman, 2015 ⁹⁷	Assess the extent to which patient participation in decision making within medical encounters is associated with measured patient outcomes.	Inception-2015	Participants = all patients; Interventions (if applicable) = attempt to increase patient participation in decisions; Comparators (if applicable) = usual care, attention control, or no choice; Outcomes = any measured patient outcome; and Study design = randomized and nonrandomized studies.	Citations with no abstract were excluded only if they clearly were not about the topic, if they were not in English, or if they were non-research articles (e.g., editorials).	Total:116 RCTs:11 Observational:105	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Winston, 2017 ⁹⁸	This study reviews the published literature on the use of video-based decision aids (DA) for patients.	NR-2016	Studies were included for full text review if they contained original data and the study included the use of a pre-produced video, a medically relevant behavioral outcome, and evidence of patient choice. Population adults and children both.	Exclusion criteria were: the use of live broadcasts, including videoconferencing and live television; exclusively static presentations such as Powerpoint; interactive visual aids such as video games. outcomes restricted to knowledge or attitude change	Total:488	Hospital and home
Shared Decision Making – Adults Only	Nathan, 2016 ⁹⁹	We conducted a systematic re- view to characterize the application and effectiveness of DAs in racial, ethnic, sexual, and gender minorities	2004-2013	Our search included English RCTs that evaluated DAs within minority populations. Based on established models of SDM and DAs, 14 we included studies with an intervention that included 1) information sharing or education and 2) risks and benefits of treatment options, to enable SDM.	Studies in which < 50 % of the participants identified as part of a racial (African American, Asian American), ethnic (Hispanic/Latino), sexual (LGB) or gender (Transgender) minority were excluded.12,16 Studies with individuals younger than 18 years old	Total:19 RCTs:19 Non-RCTs with comparison:0 Observational:0	Outpatient clinic

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Wagner, 2019 ¹⁰⁰	This review analyzes intervention and evaluation studies on patient education and continuing medical education which aim to enhance shared decision-making.	2006-2016	We included (1) studies on patient education with the aim of advancing patients' communication skills; (2) studies on continuing medical education, in which physicians received training on communication skills and how to implement shared decision-making; (3) RCTs and evaluation studies, and published between 2006 and June 2016 and be in German and/or English language.	We excluded study protocols and publications with predominantly methodological content, published before 2006 and languages other than German or English	Total:16 RCTs:11 Non-RCTs with comparison:4 Observational:1	Hospital
	Goodridge, 2019 ¹⁰¹	Scoping review to map the existing literature and describe interventions aimed at building the capacity of patients to participate in care during hospitalization by: (1) describing and categorizing the aspects of care targeted by these interventions and (2) identifying the behavior change techniques (BCTs) used in these interventions.	Inception-2017	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. All study designs were included. only English	Excluded studies: having children and adolescents; community or home settings; oncology patients, and emergency department settings. We also excluded papers focused on patient participation in research, databases, quality improvement	Total:87 RCTs:6 Non-RCTs with comparison:21 Observational:60	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Irizarry, 2015 ¹⁰²	Describe evidence for encouragement and support of patient engagement through the patient portal	2006-2014	Reports on patient experience; electronic PHR	No patient portal	Total:120 RCTs:14 Non-RCTs with comparison:4	Outpatient
	Violette, 2015 ¹⁰³	Aims to summarize and critically appraise the randomized control trials (RCTs) that have addressed the impact of decision aids on decisional outcomes (including decisional conflict and regret), patients' treatment choices, health outcomes, and health care use in the context of localized prostate cancer.	1974-2014	RCTs of a decision aid intervention for localized prostate cancer without language restrictions.	RCTs that included patients with metastatic or locally advanced disease were excluded.	Total:14 RCTs:14 Non-RCTs with comparison:0 Observational:0	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Jain, 2015 ¹⁰⁴	To evaluate the impact of video decision aids on patients' preferences regarding life-sustaining treatments (primary outcome) compared with non-video-based interventions.	1980-2014	"Study design, RCT, enrolled adult patients (age 18 years or older) in an inpatient or outpatient setting, included an arm evaluating an ACP video decision aid to assist with choices about future use of life-sustaining treatments and included a comparator arm with no ACP video decision aid and reported data on at least one outcome of interest."	Non RCTs with no comparison or did not fit the inclusion criteria	Total:10 RCTs:10 Non-RCTs with comparison:0 Observational:0	Hospital
	McIntyre, 2015 ¹⁰⁵	This review aims to establish whether computer-based learning systems (CBLs) should replace standard education for cancer populations.	2009-2013	Adult populations of patients with a pathological diagnosis of cancer, Studies comparing CBLs with SE as defined by this research, outcomes: Knowledge, satisfaction, Decision making and the effect of patient characteristics.	Excluded studies: Patients <18 years, investigating cognitively impaired and/or palliative patients and/or patients with language difficulties, CBLs alone without a SE control for comparison, development of a CBLs without reporting outcomes.	Total:8 RCTs:6 Non-RCTs with comparison:1 Observational:1	Hospital and home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Kashaf, 2015 ¹⁰⁶	Aims was to review the literature, exploring the association between SDM with regard to treatment and QOL outcomes in cancer, and to identify the variables that moderate this association.	1992-2014	Different study designs, adults (18 years) with a first-time diagnosis of cancer, option of decision making, studies measure patient participation in cancer treatment decision making and outcome as QoL, and articles published in English	None listed	Total:17 RCTs:1 Non-RCTs with comparison:2 Observational:14	Home
	Friedrichs, 2016 ¹⁰⁷	The aim is therefore to give a systematic overview of the literature of patient preferences and SDM in the treatment of patients with SUD	1980-2013	Randomized controlled trials (RCTs), quantitative studies and qualitative studies were included; Studies that evaluated interventions with either health care professionals or patients were included in this review. Studies were screened using the following inclusion criteria: 1) substance related disorder, 2) adults, 3) patient preference or 4) Shared Decision Making	1) Patients with cognitive impairments, 2) children and adolescents, 3) evaluation of patients' reasons or choices for treatment, and 4) Motivational Interviewing interventions.	Total:25 RCTs:9 Non-RCTs with comparison:0 Observational:16	Outpatient clinic

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Baik, 2018 ¹⁰⁸	The aim of this systematic literature review is to detail and compare interventions supporting SDM over the last 10 years (January 2008 to December 2017) and to analyze patient/caregiver outcomes at the end of life.	2008-2017	Studies included if they met the following criteria: (1) published between January 2008 and December 2017, (2) written in English, (3) original research study with data, (4) studies in which all patients were receiving palliative care, and (5) studies where an intervention to support SDM was conducted.	Studies were excluded if they (1) provided discussion, opinion, commentary, review, editorial, or protocol only, (2) were a published conference abstract only or presentation slides, (3) involved patients who were less than 18 years old, or (4) examined the SDM intervention for only healthcare professionals	Total:12 RCTs:6 Non-RCTs with comparison:1 Observational:5	Hospital and home
	van Weert, 2016 ¹⁰⁹	We sought to systematically review randomized controlled trials (RCTs) and clinical controlled trials (CCTs) evaluating the efficacy of decision aids as compared to usual care or alternative intervention(s) for older adults facing treatment, screening or care decisions.	Inception-2014	We included published RCTs/CCTs of interventions designed to improve shared decision making (SDM) by older adults (aged 65+) and RCTs/CCTs that analyzed the effect of the intervention in a subgroup with a mean age of 65	We excluded decision aid studies focusing on: decisions about lifestyle changes, clinical trial entry, general advance directives, general education programs; and decision aids to promote a recommended option.	Total:22 RCTs:22 Non-RCTs with comparison:0 Observational:0	Outpatient clinic, home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Berlin, 2018 ¹¹⁰	This systematic review and meta-analysis assesses the feasibility and efficacy of preoperative decision aids (DAs) to improve the patient decision-making process for breast reconstruction.	Inception-2018	Studies that met eligibility for inclusion assessed the feasibility or efficacy of a DA to improve patient decision making about post mastectomy breast reconstruction. Prospective and retrospective studies were eligible for inclusion.	Studies not reporting or assessing outcomes related to DAs to improve patient decision making about post mastectomy breast reconstruction, abstracts without an accompanying published manuscript and editorials were excluded.	Total:17 RCTs:8 Non-RCTs with comparison:3 Observational:6	Hospital
	Johnson, 2018 ¹¹¹	To determine the effectiveness of interventions to support shared decision making in hypertension.	Inception-2017	Controlled studies evaluating the effects of shared decision-making interventions for adults with hypertension compared with any comparator in any setting and reporting any outcome measures. (Only one study from the US, other from Europe)	Excluded studies reporting interventions unrelated to health-care decisions. Excluded interventions that aimed to increase the involvement of patients in their own care generally, but not in health-care decisions specifically	Total:11 RCTs:5 Non-RCTs with comparison:6 Observational:0	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Martínez-Alonso, 2017 ¹¹²	The aim of this systematic review and meta-analysis of randomized controlled trials (RCTs) and observational studies is to assess the effect of decision aids (DAs) in women aged 50 and below facing the decision to be screened for breast cancer.	Not mentioned-2016	Participants were women facing decisions about screening in a population-based screening or opportunistic case finding framework within the age interval of recommended mammography screening. Interventions: DAs were defined as interventions aimed to help women make a deliberative choice regarding participation in mammography screening.	We excluded studies aimed at elderly women only, and studies where participants were asked to make hypothetical choices. We also excluded studies aimed at increasing participation or promoting adherence, and studies not carried out in the context of women	Total:4 RCTs:3 Non-RCTs with comparison:1 Observational:0	Hospital and home
	Légaré, 2018 ¹¹³	To determine the effectiveness of interventions for increasing the use of SDM by healthcare professionals. We considered interventions targeting patients, interventions targeting healthcare professionals, and interventions targeting both.	1974-2017	Randomized and non-randomized trials, controlled before-after studies and interrupted time series studies evaluating interventions for increasing the use of SDM in which the primary outcomes were evaluated using observer-based or patient-reported measures. Participants could be any healthcare professional and patients	Not listed	Total:87 RCTs:83 Non-RCTs with comparison:3 Observational:1	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Stovell, 2016 ¹¹⁴	To examine the effects of shared decision-making on indices of treatment-related empowerment of people with psychosis	1806-2015	Trials were included if they compared a psychosocial intervention designed to enhance shared decision-making in the planning of treatment for psychosis with usual care or a non-specific control treatment. We included trials where assessing the effects of promoting shared decision-making was either a primary or a secondary aim of the study.	Studies of advance statements or care planning not involving promotion of shared decision-making were excluded, as were studies providing interventions to family members or carers.	Total:11 RCTs:11 Non-RCTs with comparison:0 Observational:0	Hospital and home
	Porter, 2016 ¹¹⁵	The published literature was systematically reviewed to determine the effect of using mobile electronic devices to record food or nutrient intake on diabetes control and nutrition outcomes	Inception-2016	Original research among people with type 1 or 2 diabetes mellitus or gestational diabetes (excluding pre-diabetes or diabetes prevention) with any treatment regimen, using mobile electronic devices where food or nutrient intake was recorded (alone or in addition to other parameters) and compared with usual care or alternative treatment models was considered.	Interventions consisting of text messages, phone calls, and access to internet or websites only were ineligible, although these were acceptable if delivered in addition to the intervention of interest described above	Total:9 RCTs:8 Non-RCTs with comparison:1 Observational:0	1 inpatient, remainder outpatient clinics

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Morrell, 2016 ¹¹⁶	To describe the range of decision aids (DAs) available to enable informed choice for older patients at the end of life (EOL) and assess their effectiveness or acceptability.	1995-2015	"All study types in English language including any modality of DAs for end of life were eligible for inclusion. Participant older patients (aged 60 years and above) with advanced or terminal illness. Outcome of interest: Effectiveness of DAs (Change in knowledge of condition or prognosis, Reduction in decisional conflict, and satisfaction with the DA, treatment decision)."	Excluded case studies due to their inability to demonstrate effectiveness but considered conference abstracts eligible to prevent publication bias as it is known that over a third of these do not result in full publication.	Total:17 RCTs:6 Non-RCTs with comparison:8 Observational:3	Outpatients, inpatients and nursing homes
	Baptista, 2018 ¹¹⁷	This meta-analysis aimed to investigate the impact of using Web-based decision aids to support men's prostate cancer screening decisions in comparison with usual care and other formats of decision aids.	Inception-2016	We included studies comparing Web-based decision aids to several parameters: (1) no intervention/usual care or (2) alternative decision aids formats. Web-based menas accessed over internet. Outcome: at least one quality of decision-making outcome (eg, knowledge, decisional conflict, and involvement in decision making).	Excluded if they did not include web-based DAs or they used computer based without internet access. Not reporting SDM outcome.	Total:7 RCTs:7 Non-RCTs with comparison:0 Observational:0	Home

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Spronk, 2018 ¹¹⁸	The aim of this review was to assess the availability and effectiveness of tools supporting SDM in metastatic breast cancer care.	2006-2017	Studies needed to focus on the development and/or evaluation of an initiative or tool that focused on i) information provision about decisions, ii) decision making process, or iii) eliciting treatment preferences in metastatic breast cancer care. Outcomes included in the studies had to be any i) patient-reported outcome, or ii) health outcome.	Not listed	Total:7 RCTs:2 Non-RCTs with comparison:2 Observational:3	Hospital
	Stacey D, 2017 ¹¹⁹	SR to assess the effects of decision aids in people facing treatment or screening decisions. Participants include adults aged 18 years or older who were making decisions about screening or treatment options for themselves, a child, or an incapacitated significant other.	2012-2015	Published randomized controlled trials comparing decision aids to usual care and/or alternative interventions in adults.	Excluded studies comparing detailed versus simple decision aid, non RCT design, qualitative studies	Total:105 RCTs:105 Non-RCTs with comparison:0 Observational:0	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Vermunt, 2017 ¹²⁰	This SR aims to identify and evaluate studies on the effects of interventions that support collaborative goal setting or health priority setting compared to usual care for elderly people with a chronic health condition or multi-morbidity.	1990-2015	RCTs, NRCTs, controlled before-after (CBA) studies, interrupted time series (ITS) and repeated measures studies. Patients with multi-morbidity or at least one chronic disease (mean age \pm standard deviation incl. age 65). Both single and multifactorial interventions supporting collaborative goal setting or health priority setting were included.	Not listed	Total:8 RCTs:5 Non-RCTs with comparison:0 Observational:3	Hospital
	Kashaf, 2017 ¹²¹	This review systematically examines, summarizes and, where possible, quantitatively synthesizes the evidence association between treatment shared decision-making (SDM) and outcomes in diabetes.	1990-2016	population composed of adults >18 years, study concern decision-making within any context of diabetes treatment or management with patient participation and studies measuring the measure process of care or clinical outcomes relevant to diabetes management.	Non-comparative designs such as case series and exploratory research and Non-longitudinal studies such as cross-sectional surveys were excluded.	Total:16 RCTs:13 Non-RCTs with comparison:1 Observational:2	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Samalin, 2018 ¹²²	This study aims to provide a review of the randomized controlled studies evaluating the effects of share decision-making (SDM) intervention in comparison to care as usual in patients with mood disorders.	2000-2017	P: Adults with mood disorders: dysthymia, MDD, or BD type I and type II., I: SDM intervention or collaborative care, which contained at least one module using a SDM process. Outcome: clinical and health related QoL, Study design: RCTs	Not listed	Total:14 RCTs:14 Non-RCTs with comparison:0 Observational:0	Hospital, PCC
	Martínez-González, 2018 ¹²³	We systematically reviewed the extent of SDM implementation in interventions to facilitate SDM for prostate cancer screening and treatment.	Inception-2015	Included studies: RCTs conducted in primary and specialized care, addressing interventions aiming to facilitate SDM for prostate cancer screening and treatment. Comparing SDM interventions to one or more alternative interventions, and/or usual care.	We excluded studies conducted in non-clinical settings and community studies in which discussions were not intended or could not occur.	Total:36 RCTs:36 Non-RCTs with comparison:0 Observational:0	Hospital, outpatient clinics, PCC
	Martínez-González, 2018 ¹²⁴	We sought to evaluate the evidence on the effectiveness of SDM as compared to current clinical practice for patient- and SDM-related outcomes. We focused on the population of men facing preference-sensitive decisions for Prostate Cancer screening.	Inception-2015	We included RCTs published in English, from any country, investigating SDM for PC screening in primary or specialized care compared SDM to usual care regardless of the intervention target.	Not listed	Total:4 RCTs:4 Non-RCTs with comparison:0 Observational:0	Hospital

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
Transitional Care – Adult Only	Sendall, 2016 ¹²⁵	This structured review will identify the components of the chronic care model (CCM) required to support healthcare that transitions seamlessly between hospital and ambulatory settings for people over 65 years of age who have two or more chronic diseases	Inception-2015	(i) involved a cohort of older people (aged >65 years) with two or more chronic diseases; (ii) involved healthcare delivery between hospital and non-hospital (i.e. primary healthcare, outpatient or community) services; (iii) involved at least two components of Wagner's CCM (i.e. healthcare organization, self-management support, delivery system design, decision support, clinical information system and community capacity); (iv) reported at least one of the following outcomes: emergency presentations, hospital admissions, health outcomes for patients or patient and clinician satisfaction with the integrated healthcare system; and (v) published in English language	(i) were not original research articles, (ii) integrated services for one chronic disease or within a health setting or (iii) did not assess an outcome of interest.	Total:4 RCTs:3 Non-RCTs with comparison:1 Observational:0	Inpatient, outpatient clinics

Type of Strategy	Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
	Berre, 2017 ¹²⁶	To determine the effectiveness of interventions targeting transitions from hospital to the primary care setting for chronically ill older patients.	1995-2016	P: 65 years old or older with at least one CD who have been hospitalized and are being discharged back to home. I: TC interventions, C: Usual care (UC) (non-structured follow up), O: All-cause mortality, Health utilization, QoL. Study design: RCTs. English or French	Not listed	Total:92 RCTs:92 Non-RCTs with comparison:0 Observational:0	Hospital and home

Evidence Table 2. Population characteristics of included systematic reviews addressing direct patient care

Type of Strategy	Author, Year	Multiple Chronic Condition	Mixed Chronic Conditions	Diabetes	Cardiovascular Disease and Hypertension	Respiratory	Cancer or Cancer Screening	Mental Health	Other
Health Literacy – Adult Only	Schaepe, 2015 ²								Kidney disease
Advanced Care Planning – Adult Only	Coulter, 2015 ¹			X	X	X		X	Kidney disease
Transitional Care – Adult Only	Berre, 2017 ¹²⁶	X							
	Sendall, 2016 ¹²⁵	X							
Shared Decision Making – Adult Only	Kashaf, 2015 ¹⁰⁶						X		
	Martínez-Alonso, 2017 ¹¹²						X		
	Stacey D, 2017 ¹¹⁹		X						
	Morrell, 2016 ¹¹⁶								End of life
	Porter, 2016 ¹¹⁵			X					
	Stovell, 2016 ¹¹⁴							X	
	van Weert, 2016 ¹⁰⁹		X						
	Spronk, 2018 ¹¹⁸						X		
	Jain, 2015 ¹⁰⁴		X						
	Irizarry, 2015 ¹⁰²		X						
	Violette, 2015 ¹⁰³						X		
	Nathan , 2016 ⁹⁹		X				X		Kidney disease
	Samalin, 2018 ¹²²							X	Depression and Bipolar disorder
	McIntyre, 2015 ¹⁰⁵						X		
	Baptista, 2018 ¹¹⁷						X		
	Légaré, 2018 ¹¹³		X						

Type of Strategy	Author, Year	Multiple Chronic Condition	Mixed Chronic Conditions	Diabetes	Cardiovascular Disease and Hypertension	Respiratory	Cancer or Cancer Screening	Mental Health	Other
	Martínez-González, 2018 ¹²⁴						X		
	Johnson, 2018 ¹¹¹				X				
	Berlin, 2018 ¹¹⁰								Surgical patients
	Baik, 2018 ¹⁰⁸								End of life
	Goodridge, 2019 ¹⁰¹								Hospitalized patients
	Wagner, 2019 ¹⁰⁰		X						
	Kashaf, 2017 ¹²¹			X					
	Vermunt, 2017 ¹²⁰	X							
	Martínez-González, 2018 ¹²³						X		
	Friedrichs, 2016 ¹⁰⁷							X	
Self-Management Support – Adult Only	Kruse, 2015 ⁸⁹		X						
	Yin, 2019 ⁹⁰		X						IBD
	Jacelon, 2016 ⁴⁰		X						
	Sangrar, 2019 ⁵⁶			X		X			diabetes, asthma, COPD
	Nazarov, 2019 ⁵⁵			X	X	X		X	Neuro
	Lederle, 2019 ⁵⁴			X	X	X	X	X	Any chronic disease (lung, heart, arthritis, diabetes, mental illness, stroke, back pain, cancer)
	Levengood, 2019 ⁵²			X					
	Han, 2019 ⁵¹			X					
	Warner, 2019 ⁵⁰		X	X	X	X			Osteoarthritis, physical rehab
	Whitehead, 2016 ²⁵			X	X	X			

Type of Strategy	Author, Year	Multiple Chronic Condition	Mixed Chronic Conditions	Diabetes	Cardiovascular Disease and Hypertension	Respiratory	Cancer or Cancer Screening	Mental Health	Other
	Palacio, 2016 ³⁸		X						
	Eeden, 2016 ³⁹		X	X		X			
	Kuo, 2016 ³³			X					
	Alessa, 2018 ⁴⁷				X				
	Smith, 2017 ⁴¹	X							
	Laukner, 2016 ⁷⁶	X		X	X			X	
	Kim, 2016 ⁴³				X	X	X	X	
	Ha Dinh, 2016 ⁵⁹			X	X	X			
	Thakkar, 2016 ⁴⁴				X	X			HIV, allergies, neuro
	Deek, 2016 ⁴⁵			X	X	X	X		Musculoskeletal
	Kim, 2015 ²⁶						X		
	Debon, 2019 ⁴⁸		X						
	Peytremann-Bridevaux, 2015 ⁷⁵					X			Asthma
	Jones, 2015 ⁸⁷								Neuro, Post-TBI, stroke patients
	Luedke, 2019 ⁴⁹								Epilepsy
	Zomahoun, 2016 ³⁷		X						
	Sakakibara, 2016 ³⁴								Neuro, Stroke patients only
	Plow, 2016 ³¹								Neuro
	Stenberg, 2016 ³⁰		X	X	X		X	X	
	Bolscher-Niehuis, 2016 ⁴⁶		X						
	Sokol, 2016 ³⁶		X						Maternal and health issues
	Hooft, 2016 ²⁹		X						
	Hecke, 2016 ²⁸		X	X					
	Teljeur, 2016 ²⁷			X					
	Pereira, 2015 ⁸⁸			X					
	Zhao, 2016 ⁵⁷			X					
	Dounavi, 2019 ⁶⁹								Obesity

Type of Strategy	Author, Year	Multiple Chronic Condition	Mixed Chronic Conditions	Diabetes	Cardiovascular Disease and Hypertension	Respiratory	Cancer or Cancer Screening	Mental Health	Other
	Whiteman, 2016 ³⁵	X						X	
	Skrabal Ross, 2018 ⁵⁸						X		
	Massimi, 2017 ⁶⁸	X		X	X				
	Clarkesmith, 2017 ⁶⁷				X				patients with atrial fibrillation
	Cho, 2017 ⁶⁶								Persons living with HIV/AIDS (PLWH)
	Kim, 2017 ⁶⁵		X	X	X	X			
	Conway, 2017 ⁶⁴			X	X				
	Jeddi, 2017 ⁶³								Kidney disease
	Kelly, 2018 ⁶²					X			
	Changizi, 2017 ⁶¹			X	X				Obesity
	Ko, 2018 ⁶⁰	X							
	Noonan, 2019 ³²				X	X			
	Price, 2015 ⁷⁰		X	X					
	Palacios, 2017 ⁷⁹				X				Patients with coronary heart disease (CHD)
	Wildevuur, 2015 ⁸⁶			X	X	X	X		Neuro
	Risling, 2017 ⁸⁴		X						
	Almutairi, 2019 ⁸²			X					
	Lee, 2018 ⁷⁷		X						
	Donald, 2018 ⁷³								Kidney disease
	Aquino, 2017 ⁷¹			X					
	Kelly, 2018 ⁸³		X						
	Warrington, 2019 ⁷⁸						X		
	Dendere, 2019 ⁸¹		X						
	Ammenwerth, 2019 ⁷²		X						

Type of Strategy	Author, Year	Multiple Chronic Condition	Mixed Chronic Conditions	Diabetes	Cardiovascular Disease and Hypertension	Respiratory	Cancer or Cancer Screening	Mental Health	Other
	Hamine, 2015 ⁸⁵			X	X	X			
	Zhao, 2015 ⁵³					X			
	Hammer, 2015 ⁴²						X		
	Boulley, 2018 ⁷⁴						X		
	Warner, 2015 ⁸⁰								Stroke, neuro
Shared Decision Making – Adults and Children	Voruganti, 2017 ⁹⁵			X	X	X		X	chronic pain, cerebral palsy, eczema
	Winston, 2017 ⁹⁸	X							Non-chronic conditions
	Kew, 2017 ⁹⁶					X			
	Clayman, 2015 ⁹⁷	X							Non-chronic conditions
Self Management Support – Adults and Children	Pamungkas, 2017 ²³			X					
	Kew, 2016 ¹⁸					X			
	Hill, 2015 ²²	X							
	Barello, 2016 ¹⁴							X	HIV
	Graham, 2016 ¹⁹			X		X		X	Kidney disease, Cerebral Palsy, Brain Injury
	Niznik, 2018 ¹³			X	X	X		X	Kidney disease, hyperlipidemia
	Bashi, 2018 ¹⁵	X						X	
	Lycett, 2018 ¹⁶					X			
	Lancaster, 2018 ¹⁷			X		X	X		
	Yin, 2019 ²⁰			X	X	X		X	Kidney disease, Parkinson disease
	Chi, 2015 ²¹			X				X	Kidney disease, Parkinson disease
	Kruse, 2015 ²⁴	X							
	Wyatt, 2015 ⁹⁴							X	ADHD, Heme/Onc, HIV, developmental disabilities
Shared Decision Making – Children Only	Coyne, 2016 ⁹³						X		
	Cheng, 2017 ⁹²							X	

Type of Strategy	Author, Year	Multiple Chronic Condition	Mixed Chronic Conditions	Diabetes	Cardiovascular Disease and Hypertension	Respiratory	Cancer or Cancer Screening	Mental Health	Other
Self Management Support – Children Only	Malone, 2019 ⁹¹				X				CF
	Clemente, 2016 ¹²								Rheumatologic/MS K
	Hamline, 2018 ¹¹	X		X	X	X	X	X	sickle cell disease, CCF, epilepsy
	Sattoe, 2015 ¹⁰			X		X			
	Charlier, 2015 ⁹			X		X	X		
	Majeed-Ariss, 2015 ⁸			X		X	X		
	Campbell, 2016 ⁷			X					cystic fibrosis, inflammatory bowel disease, spina bifida
	Knafl, 2017 ⁶			X	X	X	X		cystic fibrosis, blood disorders, fibromyalgia
	Saxby, 2018 ⁵			X	X	X			
	Low, 2019 ⁴	X		X	X	X			Rheumatic
	Bal, 2015 ³			X	X	X	X		cystic fibrosis, sickle cell disease, spina bifida

Evidence Table 3. Intervention characteristics of included systematic reviews addressing direct patient care

Type of Strategy	Author, Year	Description of Intervention	Modality
Advanced Care Planning – Adults Only	Coulter, 2015 ¹	All 19 studies included components that were intended to support behavior change among patients, involving either face-to-face support or telephone support; A variety of tools and techniques were used in the interventions, including patient information	Education/counseling
Health Literacy – Adults Only	Schaepe, 2015 ²	Most of the 18 included studies focused on educational intervention programs for people undergoing peritoneal dialysis.	Education/counseling
Transitional Care – Adults Only	Sendall, 2016 ¹²⁵	Each of the studies used clinical information sharing, community linkages and supported self-management components of the CCM to create a seamless transition across services for older people with two or more chronic diseases.	Multiple modalities
	Berre, 2017 ¹²⁶	Educational components (e.g., motivational interview/individualized face-to-face coaching, brochures, videotape) (94.6%), and medication management (55.4%). multidisciplinary coordination process. Phone contacts (59.2%) or home visits (59.8%), and provide	Nurse/case managers
Self Management Support – Adults Only	Yin, 2019 ⁹⁰	Mobile health Apps directed education and management of IBD	Mobile health
	Kruse, 2015 ⁸⁹		Patient portal
	Whiteman, 2016 ³⁵	Automated Telehealth, Health and Recovery Peer program (HARP), Integrated Illness Management and Recovery, HOPES, All these interventions targeted a heterogeneous set of serious mental illnesses and medical illnesses that require ongoing treatment.	Nurse/case managers
	Nazarov, 2019 ⁵⁵	Workplace oriented intervention programs; Cognitive behavioral therapy interventions; Self-management programs; Vocational rehabilitation programs; Coaching interventions; Comparative intervention strategies; Interventions that prevent or slow down chronic	Multiple modalities
	Zhao, 2016 ⁵⁷	Theory of empowerment (Presentation, discussion and Reflection), Extended health belief model (Pamphlets and face to face lecture, question and answer), Diabetes conversation maps program (goal settings, group discussion), Problem-based learning	Nurse/case managers
	Teljeur, 2016 ²⁷	Education with self management training and with computer-assisted self care, Lifestyle modification program, Printed materials and telephone counselling, 6-h structured group education program, Automated uploading of blood, Telemedicine - blood glucose	Nurse/case managers
	Hecke, 2016 ²⁸	Self Management Support Interventions (lifestyle advice, education for diseases and symptom management, Problem-solving, goal-setting delivered through face to face, telephone, video conference)	Nurse/case managers
	Hooft, 2016 ²⁹	Educational and counselling components; some involved physical exercises, Family involvement sessions, interventions were provided in group sessions, sometimes combined with individual sessions. Mostly in person.	Nurse/case managers
	Stenberg, 2016 ³⁰	In person counseling programs such as Diabetes Peer to Peer program, Learning and mastery/Educational lifestyle courses, self-management programs	Peer/lay support'
	Plow, 2016 ³¹	Interventions = emotion and pain management strategies, physical activity training, Behavior Change Techniques delivered through One-to-one, in-person then distant follow up through web and phone.	Nurse/case managers

Type of Strategy	Author, Year	Description of Intervention	Modality
	Sakakibara, 2016 ³⁴	Self management interventions, feedback on performance, goal setting/action planning and problem solving through in person and telephone sessions. both individual and group formats	Nurse/case managers
	Massimi, 2017 ⁶⁸	Health educational program±LAY (Look After Yourself), "Care Guide" (care plan) and an Action Plane (patient's self-care plane) delivered face-to-face, face-to-face/telephone, nurse visits at patients home or nurse specific clinics, CHCs	Nurse/case managers
	Bolscher-Niehuis, 2016 ⁴⁶	Core elements of the self-management support program were: health promotion and information about the disease, education aimed at knowledge, skills and strategies to manage the consequences of the disease/disability, coaching of health behavior change	Nurse/case managers
	Sokol, 2016 ³⁶	Regular communication between peer supporter and participant usually in 2 weeks, feedback, contact monitoring and record keeping. Community partnerships. Tailored content was also reported (n = 8), with peer supporters recognizing participants' needs and	Peer/lay support'
	Whitehead, 2016 ²⁵	An app plus feedback or contact with participants either by text or phone conversation, App based diseases specific education, App based teleconsultation intervention.	Mobile Health
	Palacio, 2016 ³⁸	Motivational Interviewing, counseling, (Face to face, phone calls, both, computer-based, individual and in group sessions)	Nurse/case managers
	Debon, 2019 ⁴⁸	Reminders for follow up through messages, sending alerts, logs of blood glucose, eating habits, lifestyle change education.	Mobile Health
	Eeden, 2016 ³⁹	Nurse led Educational program. Guided SMI with education and training of skills provided by a family physician. Internet based SMI including online/group-based education according to a computerized personal action plan.	Nurse/case managers
	Kuo, 2016 ³³	Secure messaging in electronic health records	Patient Portal
	Jacelon, 2016 ⁴⁰	SMI: Disease Focused education, Peripherals, Feedbacks, Diary, Provider access, User education. Provider consultations, Sensor based technology use	Multiple technologies
	Noonan, 2019 ³²	Behavior change in adults (Digital weighing scale, Medication box. Calibrated bottle, Diary), Model of health promotion and Bandura's self-efficacy theory (Computer & CD ROM Written teaching materials), Dialogue guides, Content of conversation, Education	Nurse/case managers
	Warner, 2019 ⁵⁰	Arthritis Self-management Program (Goals, Problem solving, Action planning, Skill Building). Guided Care Goals (Problem solving, Action planning, Education, Skill building, Education, Monitor). Strategies included Process, Health Behavior change	Nurse/case managers
	Changizi, 2017 ⁶¹	Call cell phone, text messages, mobile app	Mobile Health
	Kelly, 2018 ⁶²	We specified that interventions should include collaborative interaction between participants and healthcare providers, involving goal setting and feedback, with at least two points of contact, and that specific program should include at least two of	Education/Counseling
	Levengood, 2019 ⁵²	Team based care - patient education and counseling, either in person or remote	Team based care

Type of Strategy	Author, Year	Description of Intervention	Modality
	Jeddi, 2017 ⁶³	Interventions were delivered via smartphones/personal digital assistants (PDAs) (three studies), wearable devices (three studies), computerized systems (one study), and multiple component (one study).	Mobile Health
	Kim, 2015 ²⁶	Automated functions in 16 interventions. Supplementary modes were used in 16 interventions. The most widely used function in the automated functions category was “the use of an enriched information environment” (n=17), and the most widely used function in	Other technology
	Alessa, 2018 ⁴⁷	The intervention was a mobile phone or a tablet app that collects data, provides feedback, connects with HCPs or informs about hypertension to support the self-management tasks of hypertension	Mobile Health
	Smith, 2017 ⁴¹	At organizational level (Case management or coordination of care, Reorganization of care/team working, Nurse training), At individual level (Individual management plans Support for self management, Personalized goals and participant workbooks, Individual	Nurse/case managers
	Zomahoun, 2016 ³⁷	Motivational Interviewing (Face to face, phone calls, both, computer-based, individual and in group sessions)	Nurse/case managers
	Skrabal Ross, 2018 ⁵⁸	mobile phone–delivered interventions - SMS text messages and mobile apps; Despite the variety of adherence-enhancing strategies in the interventions, 2 strategies were common to most studies: drug-related symptom management advice and reporting and medical	Mobile Health
	Sangrar, 2019 ⁵⁶	education programs that combined face-to-face and online/ computer-based strategies delivered or mediated by healthcare professionals	Multiple modalities
	Luedke, 2019 ⁴⁹	Educational (sign/symptom monitoring; enhancing problem-solving, Medications management and decision-making skills) and psychosocial therapy interventions (eg, cognitive behavioral therapy, problem solving therapy, progressive muscle relaxation)	Nurse/case managers
	Kim, 2017 ⁶⁵	self-monitoring, automated feedback, patient education and decision making using smartphone Apps	Mobile Health
	Lederle, 2019 ⁵⁴	Structured program for individuals with chronic diseases administered by trained affected persons who are helping patients to improve their own health	Peer/lay support'
	Dounavi, 2019 ⁶⁹	mHealth apps - Main app components were the provision of health-related information, feedback, reminders, peer support groups, goal setting, food and physical activity logging, weight self-monitoring, digital coaching, and exceptional blood pressure tagging	Mobile Health
	Conway, 2017 ⁶⁴	Strategies used to improve medication adherence included four primary approaches: IVR (with or without human interaction), SMS text messaging, telemonitoring and/or tailored care management, and Web-based software	Multiple technologies
	Cho, 2017 ⁶⁶	eHealth (computer-based system, Internet-based program, and Health Information Exchange), mHealth (Apps), Telehealth (phone calls and telemedicine), Web-based decision support system + telephone-based monitoring	Multiple technologies

Type of Strategy	Author, Year	Description of Intervention	Modality
	Clarkesmith, 2017 ⁶⁷	Self Monitoring and education (one to one, group training sessions, Video component, educational booklet), decision support aid employed pictograms and computerized version	Nurse/case managers
	Ko, 2018 ⁶⁰	Collaborative care, psychiatric illness self-management, nurse led self management sessions, communications with physicians	Nurse/case managers
	Han, 2019 ⁵¹	Individual and group education sessions with some studies including telephone/electronic follow ups	Education/Counseling
	Kelly, 2018 ⁸³	Patient portals for hospitalized patients	Patient Portal
	Hamine, 2015 ⁸⁵	mHealth included any mobile device or service, such as mobile phones, SMS, smartphones, personal digital assistants, and devices that work on wireless technology or Bluetooth-compatible devices	Mobile Health
	Hammer, 2015 ⁴²	There were various types of educational and/or counseling sessions that guided patients toward self-assessment and management of cancer/treatment-related challenges. The major commonality of these programs included cognitive-behavioral type therapies of	Education/Counseling
	Zhao, 2015 ⁵³	Internet-based management (electronic diary, treatment decision support, monitoring support by a study nurse) plus physician office visits, SMS monitoring to assist managing asthma control, Interactive voice response, Internet-based self management program	Multiple technologies
	Almutairi, 2019 ⁸²	Interventions based on patient activation concept which focuses on patient knowledge, skills and confidence building. Includes Motivational interviewing, Patient empowerment, patient-centered tailored care, PRECEDE- PROCEED model, health action process app	Nurse/case managers
	Dendere, 2019 ⁸¹	Patient portals tethered to an electronic medical record in inpatient settings	Patient Portal
	Wildevuur, 2015 ⁸⁶	Initially defined PCC-ICT as a category of Internet technology that connects patients to health care professionals and enables them to interact and exchange information, including multimedia data such as audio (voice), video, and images.	Multiple technologies
	Boulley, 2018 ⁷⁴	live video conferencing, online interactive workshops, websites including social networks for synchronous or asynchronous communication, text messages, automated voice response, PA tracking devices or Wi-Fi weighing scales associated with an app. Follow-up	Multiple technologies
	Ammenwerth, 2019 ⁷²	Patient portals with electronic health record access.	Patient Portal
	Aquino, 2017 ⁷¹	individual consultations, phone calls, sessions via a website and use of a booklet, daily sessions through a tablet and also shared their blood glucose data and received feedback through individual messages via tablet	Nurse/case managers
	Donald, 2018 ⁷³	intervention were face to face (80%), telephone, email, print version (64%), Electronic i-e website, mobile applications (16%)	Multiple modalities
	Lee, 2018 ⁷⁷	real-time or regular basis symptom assessments, monitoring of disease, pre-programed reminders, or feedbacks tailored specifically to the data provided by participants via mHealth devices or mobile apps. Training of mHealth systems was provided to participants	Mobile Health
	Risling, 2017 ⁸⁴	Tethered patient portals providing access to electronic health records	Patient Portal

Type of Strategy	Author, Year	Description of Intervention	Modality
	Palacios, 2017 ⁷⁹	1. Web site and online forums plus tailored intervention Vs Generic version of the Web site and an online forum. 2. Internet-delivered cognitive behavior therapy Vs Internet-delivered attention control health information package. 3. text messages	Multiple technologies
	Pereira, 2015 ⁸⁸	Internet education Vs face-to-face diabetes education comparison, online DSME program, Diabetes coach Web program (interactive, personalized profile, nurse/patient e-mail), interactive Web program for tracking food intake and glucose levels; e-mail feature	Telehealth
	Warrington, 2019 ⁷⁸	Main Interventions: 1. communication with HCPs, 2. Disease monitoring (HCPs to remotely access and monitor patient reported data, give feedback) 3. Symptom management (provide tailored advice for symptom or side effect management)	Multiple technologies
	Deek, 2016 ⁴⁵	All studies involved face to face educational sessions with the patients and their caregivers. However, the type of sessions and the follow-up varied across the studies. Three categories of interventions were identified: self-care strategies, coping ski	Education/Counseling
	Laukner, 2016 ⁷⁶	Four programs using telecommunications only (including one or more of the following: websites, discussion boards, emails, telephone and/or telehealth), four using in-person meetings only and two combining telecommunication and in-person; Peer leaders in	Peer/lay support'
	Price, 2015 ⁷⁰	Range of PHR functions: Access medical record; record personal health data , communicate with support group, communicate with providers, manage care plan.	Patient portal
	Kim, 2016 ⁴³	The roles assumed by CBHWs included health education (n = 48), counseling (n = 36), navigation assistance (n = 21), case management (n = 4), social services (n = 7), and social support (n = 18).	Community health worker/patient navigator
	Ha Dinh, 2016 ⁵⁹	There was little consistency among studies in relation to delivery method, duration, educational components and persons who conducted the health education programs; Interventions involved educational content delivered with the teach- back method in one-on	Education/Counseling
	Thakkar, 2016 ⁴⁴	Text messaging systems - Fifteen studies sent text messages at a fixed predetermined frequency; One study used real-time medication monitoring in which patients were sent a text message reminder only if the participant failed to open the medication dispenser	Mobile Health
	Jones, 2015 ⁸⁷	All the interventions included at least some element of face-to- face delivery; however, two studies delivered the majority of their intervention remotely via telephone; The three studies that utilized only face-to-face delivery all did this via group session	Education/Counseling
	Peytremann-Bridevaux, 2015 ⁷⁵	we considered the following five criteria for our operational definition of CDM: 1. at least one organizational component (i.e., elements that interfere with the care process or that aim to improve continuity of care) targeting patients (Steuten 2007a;	multiple modalities
	Warner, 2015 ⁸⁰	goal setting, follow-up, and an individualized approach using structured information and professional support	Nurse/case managers

Type of Strategy	Author, Year	Description of Intervention	Modality
Self Management Support – Adults and Children	Lancaster, 2018 ¹⁷	eHealth tool was considered to be any internet-based intervention, including mobile health apps, used by patients for clinical purposes that focused on improving patient health and clinical outcomes; patients and/or caregivers can directly enter or edit h	Multiple technologies
	Barello, 2016 ¹⁴	Heterogeneous group - Web based portals, some monitoring capabilities, communication tools, counseling/therapy, patient specific information - some self reported	Multiple technologies
	Kruse, 2015 ²⁴	Patient portals for the management of chronic disease	Patient Portal
	Yin, 2019 ²⁰	Patient-facing technologies: Acceleration sensors, Earphones and wearable computer, Wireless BP monitor, Mobile App, Environmental sensors, Exhaled air sensor	Multiple technologies
	Pamungkas, 2017 ²³	Individual or group sessions including personalized counseling, goal-setting, problem solving, and explanation of ways in which family members can support self-care practice and follow-up sessions (computer-based, phone call, short message service (mail)	multiple modalities
	Chi, 2015 ²¹	There were six main categories of interventions delivered via technologies: education (37%), consultation (including decision support aid) (37%), psychosocial/cognitive behavioral therapy (including problem solving training) (35%), social support (23%),	Multiple technologies
	Niznik, 2018 ¹³	Clinical pharmacy telemedicine interventions in the outpatient or ambulatory setting; telephone (n = 25), video consultation (n = 4), text or electronic messaging (n = 3), e-mail (n = 2), automated electronic reports (n = 1), and fax (n = 1).	Telehealth
	Kew, 2016 ¹⁸	We included studies comparing home telemonitoring of asthma between clinic visits, using any form of technology (e.g. telephone calls, emails, text messages, online software), with a form of monitoring that does not include ongoing remote professional fee	Telehealth
	Lycett, 2018 ¹⁶	Interventions were classified as fully digital or partly digital (digital and non digital components). Data were extracted on the type of digital platform (eg, SMS, smart device app) and the type of non digital component (eg, telephone call, paper-based).	Multiple modalities
	Hill, 2015 ²²	Motivational interviewing, Cognitive behavioral therapy and social cognitive theory based approaches. Included behavior change techniques were Goal settings, action planning, barrier identification/problem solving, prompt self-monitoring of behavior	Nurse/case managers
	Bashi, 2018 ¹⁵	Text and Video clips in smartphone App delivered educational material about causes of diseases, monitoring signs and symptoms, exercise instructions, diet recommendations, and coping strategies.	Mobile Health
	Graham, 2016 ¹⁹	Acceptance and commitment therapy - either individual or group	Education/Counseling
Self Management Support – Children Only	Knafl, 2017 ⁶	intervention had to be psychologically, socially, or behaviorally oriented and include participation by the child's parent(s) or primary caregiver(s) (hereafter referred to as parents); Interventions were predominantly psychoeducational (n = 55; 79%), wit	Education/Counseling

Type of Strategy	Author, Year	Description of Intervention	Modality
	Sattoe, 2015 ¹⁰	Medical management, role management (communicating, decision-making, assertiveness, and keeping up with peers), emotional management (building self-confidence, developing a positive body image, self- appreciation, maintaining positive thinking, stress man	Education/Counseling
	Low, 2019 ⁴	Static text to audiovisual materials, games using mHealth Apps and Web-based technology	Multiple technologies
	Hamline, 2018 ¹¹	(1) interventions involving communication between the inpatient and outpatient health care providers (provider communication interventions [PCIs]), (2) interventions involving care coordination (CCIs, defined as those that involved intentional organization	multiple modalities
	Clemente, 2016 ¹²	All transitional care programs had a written transition policy and protocol agreed by the pediatric and adult teams that described in detail the transition process. Two components of these programs were of particular importance: (1) information and e	Education/Counseling
	Bal, 2015 ³	medical management (61.9%), e.g. self- monitoring of blood glucose values in diabetes, accessing healthcare, but also child-parent sharing or teamwork related to medical management tasks. Interventions included education (88.1%), peer-support (23.8%), pro	multiple modalities
	Campbell, 2016 ⁷	The four studies explored different types of interventions: transition- preparation training (TPT) delivered in a two-day workshop for adolescents with spina bifida; a web- and SMS-based educational intervention for adolescents with a range of different c	multiple modalities
	Charlier, 2015 ⁹	Within the game intervention group, patients played a video game with educational content aiming at knowledge improvement or promotion of self-management behaviors. Games were software packages that run on a personal computer, console, or mobile phone.	Other technology
	Saxby, 2018 ⁵	Education interventions grouped in to the following: Directive learning (i.e., involves the use of a structured evidence- based curriculum to teach skills and knowledge to children); Active and experiential learning	Education/Counseling
	Majeed-Ariss, 2015 ⁸	The commonality among all apps studied was that they aimed to support the adolescent in the medical management of their physical condition. Cafazzo et al's [55] and Frøisland et al's [56] apps for type 1 diabetes management focused on increasing the number	Mobile Health
Shared Decision Making – Adult Only	Baik, 2018 ¹⁰⁸	Technology-enabled delivery modes (e.g., video, DVD, web-based tool), print materials, palliative care consultation and structured meeting between patients/ caregivers and inter professional care team. Other were Goals of Care video decision aid, booklet a	Nurse/case managers
	Martínez-González, 2018 ¹²³	Face-to-face, by telephone, consultations, questionnaires, paper based material and web-based format. Elements of interventions were weighing up benefits and harms", "risks", "pros and cons of options", "patients' values", "preferences"	Multiple modalities

Type of Strategy	Author, Year	Description of Intervention	Modality
	Samalin, 2018 ¹²²	Physician training, a decision board for use during the consultation and printed patient information, SDM based on pharmacist intervention, Collaborative care with: Care management, Patient treatment preference, Shared decision-making with a decision board	Education/Counseling
	Spronk, 2018 ¹¹⁸	Decision aid tools: CONNECT (communication aid that assesses patient preferences and values, and includes communication skills training, plus summary report to the physician), State-of-the-art tables with information for patients with advanced breast Ca a	Other technology
	Baptista, 2018 ¹¹⁷	Web based decision aids (with information about PC and screening, pros and cons of PSA testing, experiences of other patients, values clarification exercise) only or Web based decision and paper-based decision aids vs no interventions,	Telehealth
	Martínez-González, 2018 ¹²⁴	Interactive web-based physician educational program (30 min) with information about PC and screening + web-based patient activation, CDC brochure about PC, Flyer about PC and PSA screening with patient encouragement to talk with providers, Web-based information	Education/Counseling
	Vermunt, 2017 ¹²⁰	Educations sessions and coaching for patients. Guided Care, monitoring by telephone with reminders from the HER. Training for care provider	Nurse/case managers
	Martínez-Alonso, 2017 ¹¹²	Web-based DA, information on possible screening outcomes and worksheet to help weigh up and clarify preferences. Web-based DA in three rural clinical settings, including BC information and questions for risk and self-preferences assessment. Mailed leaflet	Nurse/case managers
	Berlin, 2018 ¹¹⁰	An exercise for patients to clarify their values and preferences in the context of breast reconstruction. All DAs included educational components regarding the different approaches to breast reconstruction, including the reconstruction-related risks.	Education/Counseling
	Légaré, 2018 ¹¹³	Interventions targeting patients: decision aids, brochure, patient activation and empowerment sessions, question prompt lists and training for patients in SDM. Interventions targeting healthcare professionals included educational meetings, educational material	Education/Counseling
	Kashaf, 2017 ¹²¹	Provider/nurse led sessions, audiotaped patient education sessions, Statin Choice decision aid, interactive Diabetes Decision Aid Vs usual care/one time education alone.	Nurse/case managers
	Goodridge, 2019 ¹⁰¹	Multifaceted interventions involving a patient-centered 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 p	Nurse/case managers
	Wagner, 2019 ¹⁰⁰	Patient trainings and education which aimed to enable patients to ask more questions during a consultation and to make decisions together with their physicians. Continuing medical education for health care providers (Workshop with video modelling, ideal	Nurse/case managers

Type of Strategy	Author, Year	Description of Intervention	Modality
	Johnson, 2018 ¹¹¹	Intervention components included training interventions for clinicians, coaching for patients, decision aids and written materials for patients. shared decision-making training program for general practitioners. Previsit coaching, by community health wo	Education/Counseling
	Kashaf, 2015 ¹⁰⁶	Decision aid (booklet and audiotape/disc facilitating SDM), Perceived treatment choice,	Education/Counseling
	Violette, 2015 ¹⁰³	Audio recording of clinical encounter, Written information printout, CCE information booklet, Communication strategy intervention via DVD and 4 telephone calls, Tailored internet aid	Nurse/case managers
	Irizarry, 2015 ¹⁰²	Patient experience and/or ways that patients may be supported to make competent health care decisions and act on those decisions using patient portal functionality.	Patient Portal
	McIntyre, 2015 ¹⁰⁵	computer-based learning systems (CBLs) providing patient education about decision making, treatment options . A Web-based communication aid for patients with cancer, The impact of an empowering Internet-based Breast Cancer Patient Pathway program.	Other technology
	Friedrichs, 2016 ¹⁰⁷	Physician led counseling and SDM sessions with paper prompts; computerized tailored decisional support tool;	Education/Counseling
	van Weert, 2016 ¹⁰⁹	Decision aids were defined as “interventions designed to help people make specific and deliberative choices among options (including the status quo) by making the decision explicit and by providing (at the minimum) information on the options and outcomes	Education/Counseling
	Nathan, 2016 ⁹⁹	Many of the trials attempted to test their SDM intervention through multiple modalities (Table 3). Eight studies utilized more than one method to deliver their intervention (e.g., print and phone counseling), and the remaining ten studies used one method	Multiple modalities
	Stovell, 2016 ¹¹⁴	Interventions designed to support shared decision-making in relation to current and future treatment. Paper-based or web-based decision or communication aids. one evaluated a group intervention;30 another evaluated the effects of training clinicians in a	Multiple modalities
	Porter, 2016 ¹¹⁵	multi-component diabetes management strategy- dietary data was recorded in addition to a range of other medical information (e.g., blood glucose levels, medications, physical activity); Interventions were delivered via a mobile phone applications	Multiple technologies
	Stacey D, 2017 ¹¹⁹	Patient decision aids that included information about the options and outcomes and provided at least implicit clarification of values. Guidance and coaching for patients and training for physicians as well.	Nurse/case managers
	Morrell, 2016 ¹¹⁶	Decision aids in form of Self-paced audio and video, Self-guided and interactive computerized and surrogate involvement such as clinician, staff, parents, family members (Only for patients with dementia or without decision-making capacity). Other: patient	Nurse/case managers

Type of Strategy	Author, Year	Description of Intervention	Modality
	Jain, 2015 ¹⁰⁴	video decision aids to assist with ACP e.g: a narrative description of CPR, and likelihood of its success in patients with advanced cancer or Verbal description by research staff followed by video.	Other technology
Shared Decision Making – Adults and Children	Clayman, 2015 ⁹⁷	physician training and decision aid use for patients. Patient physician treatment discussions and SDM.	Education/Counseling
	Kew, 2017 ⁹⁶	SDM intervention for patients and HCPs. SDM seminars for HCPs. SDM portal and SDM online tool for patients/parents and HCPs. Two pediatric studies involved use of an online portal, followed by face-to-face consultations. clinical decision-making intervention	Education/Counseling
	Winston, 2017 ⁹⁸	Video based DAs	Other technology
	Voruganti, 2017 ⁹⁵	Of the 47 tools identified, the majority (74.5%, 35/47) were Internet-enabled applications accessible from a Web browser, whereas 9 (19%, 9/47) were native applications developed as computer software or for use on a mobile phone.	Multiple technologies
Shared Decision Making – Children Only	Wyatt, 2015 ⁹⁴	Online, web-based; in person sessions; paper formats	multiple modalities
	Malone, 2019 ⁹¹		Education/Counseling
	Cheng, 2017 ⁹²	therapeutic techniques, decision aids, psychoeducational information, action planning or goal setting, discussion prompts, and mobilizing patients to engage	multiple modalities
	Coyne, 2016 ⁹³	Interventions that promote SDM between children with cancer and parents and healthcare professionals	Education/Counseling

Evidence Table 4. Outcomes of included systematic reviews addressing direct patient care

Type of Strategy	Author, Year	Caregiver-Related Measures	Implementation Measures / Fidelity Elements	Clinical Staff Behavior Change	Cost / Value	Clinician Behavior Change	Provider Satisfaction	System Level Changes	Medication or Self-Management Adherence	Chronic Disease Clinical Outcomes (e.g. A1c, BP)	Patient Reported Outcomes (e.g. Satisfaction and Quality of Life)	Mortality	Quality of Life	Health Care Utilization, Including Re-admissions; overuse of ER	Patient Satisfaction / Experience	Decisional Support Outcome
Advanced Care Planning – Adults Only	Coulter, 2015 ¹								X	X				X		
Health Literacy – Adults Only	Schaepe, 2015 ²									X			X		X	
Self Management Support – Adults Only	Kruse, 2015 ⁸⁹									X					X	
	Yin, 2019 ⁹⁰	X							X	X			X		X	
	Debon, 2019 ⁴⁸								X	X			X			
	Luedke, 2019 ⁴⁹								X	X			X	X		
	Warner, 2019 ⁵⁰								X	X			X			
	Han, 2019 ⁵¹				X				X	X	X					
	Levengood, 2019 ⁵²									X	X	X		X		
	Lederle, 2019 ⁵⁴													X		
	Nazarov, 2019 ⁵⁵												X			
	Sangrar, 2019 ⁵⁶								X	X			X			
	Dounavi, 2019 ⁶⁹								X	X					X	
	Skrabal Ross, 2018 ⁵⁸		X						X							
	Alessa, 2018 ⁴⁷									X					X	
	Ko, 2018 ⁶⁰								X	X				X		
	Changizi, 2017 ⁶¹								X	X						
	Kelly, 2018 ⁶²									X			X			
	Jeddi, 2017 ⁶³								X	X						
	Conway, 2017 ⁶⁴								X							
	Kim, 2017 ⁶⁵								X	X						X
	Cho, 2017 ⁶⁶												X			
	Clarkesmith, 2017 ⁶⁷								X	X					X	X
	Massimi, 2017 ⁶⁸								X	X			X			
	Zomahoun, 2016 ³⁷								X							
	Whiteman, 2016 ³⁵								X	X				X		
	Zhao, 2016 ⁵⁷								X	X			X			

Type of Strategy	Author, Year	Caregiver-Related Measures	Implementation Measures / Fidelity Elements	Clinical Staff Behavior Change	Cost / Value	Clinician Behavior Change	Provider Satisfaction	System Level Changes	Medication or Self-Management Adherence	Chronic Disease Clinical Outcomes (e.g. A1c, BP)	Patient Reported Outcomes (e.g. Satisfaction and Quality of Life)	Mortality	Quality of Life	Health Care Utilization, Including Re-admissions; overuse of ER	Patient Satisfaction / Experience	Decisional Support Outcome
	Teljeur, 2016 ²⁷								X	X				X		
	Hecke, 2016 ²⁸								X	X				X		
	Hooft, 2016 ²⁹								X	X						
	Stenberg, 2016 ³⁰								X	X			X			
	Plow, 2016 ³¹								X	X						
	Noonan, 2019 ³²								X				X			
	Sakakibara, 2016 ³⁴								X	X						
	Bolscher-Niehuis, 2016 ⁴⁶								X				X			
	Sokol, 2016 ³⁶			X					X						X	
	Whitehead, 2016 ²⁵								X	X						
	Palacio, 2016 ³⁸								X							
	Eeden, 2016 ³⁹								X				X	X		
	Kuo, 2016 ³³									X						
	Jacelon, 2016 ⁴⁰								X							
	Smith, 2017 ⁴¹				X	X		X	X	X			X	X		
	Laukner, 2016 ⁷⁶								X	X					X	
	Kim, 2016 ⁴³				X					X						
	Ha Dinh, 2016 ⁵⁹								X				X	X		
	Thakkar, 2016 ⁴⁴								X							
	Deek, 2016 ⁴⁵				X				X			X	X	X		
	Kim, 2015 ²⁶									X			X			
	Peytremann-Bridevaux, 2015 ⁷⁵				X				X	X			X	X		
	Jones, 2015 ⁸⁷								X				X		X	
	Price, 2015 ⁷⁰									X					X	
	Wildevuur, 2015 ⁸⁶				X				X				X	X		
	Hamine, 2015 ⁸⁵		X						X	X						

Type of Strategy	Author, Year	Caregiver-Related Measures	Implementation Measures / Fidelity Elements	Clinical Staff Behavior Change	Cost / Value	Clinician Behavior Change	Provider Satisfaction	System Level Changes	Medication or Self-Management Adherence	Chronic Disease Clinical Outcomes (e.g. A1c, BP)	Patient Reported Outcomes (e.g. Satisfaction and Quality of Life)	Mortality	Quality of Life	Health Care Utilization, Including Re-admissions; overuse of ER	Patient Satisfaction / Experience	Decisional Support Outcome
	Hammer, 2015 ⁴²									X			X			
	Zhao, 2015 ⁵³								X	X						
	Ammenwerth, 2019 ⁷²								X						X	
	Dendere, 2019 ⁸¹		X							X					X	
	Warrington, 2019 ⁷⁸								X	X			X		X	
	Boulley, 2018 ⁷⁴												X	X	X	
	Kelly, 2018 ⁸³															
	Aquino, 2017 ⁷¹								X	X			X			
	Donald, 2018 ⁷³								X				X		X	
	Lee, 2018 ⁷⁷								X	X			X			
	Risling, 2017 ⁸⁴														X	
	Palacios, 2017 ⁷⁹								X	X			X			
	Pereira, 2015 ⁸⁸								X	X						
	Warner, 2015 ⁸⁰								X				X	X	X	
	Almutairi, 2019 ⁸²								X	X						
Self Management Support – Adults and Children	Yin, 2019 ²⁰								X	X						
	Lancaster, 2018 ¹⁷								X	X				X	X	
	Lycett, 2018 ¹⁶								X	X			X	X		
	Bashi, 2018 ¹⁵								X	X						
	Niznik, 2018 ¹³								X	X						
	Kew, 2016 ¹⁸									X			X			
	Graham, 2016 ¹⁹								X				X			
	Kruse, 2015 ²⁴						X								X	
	Chi, 2015 ²¹								X				X			
	Hill, 2015 ²²								X	X			X			
	Pamungkas, 2017 ²³								X	X						
	Barello, 2016 ¹⁴								X						X	
Self-Management Support – Children Only	Low, 2019 ⁴								X				X		X	

Type of Strategy	Author, Year	Caregiver-Related Measures	Implementation Measures / Fidelity Elements	Clinical Staff Behavior Change	Cost / Value	Clinician Behavior Change	Provider Satisfaction	System Level Changes	Medication or Self-Management Adherence	Chronic Disease Clinical Outcomes (e.g. A1c, BP)	Patient Reported Outcomes (e.g. Satisfaction and Quality of Life)	Mortality	Quality of Life	Health Care Utilization, Including Re-admissions; overuse of ER	Patient Satisfaction / Experience	Decisional Support Outcome
	Saxby, 2018 ⁵								X				X			
	Knafl, 2017 ⁶								X	X			X			
	Clemente, 2016 ¹²								X	X			X			
	Campbell, 2016 ⁷								X	X			X			
	Bal, 2015 ³								X	X			X			
	Majeed-Ariss, 2015 ⁸								X	X						
	Charlier, 2015 ⁹								X							
	Sattoe, 2015 ¹⁰									X			X			
Shared Decision Making – Adults Only	Hamline, 2018 ¹¹													X		
	Vermunt, 2017 ¹²⁰					X										X
	Kashaf, 2017 ¹²¹								X	X			X			X
	Wagner, 2019 ¹⁰⁰					X	X								X	X
	Goodridge, 2019 ¹⁰¹								X						X	X
	Baik, 2018 ¹⁰⁸	X													X	X
	Berlin, 2018 ¹¹⁰														X	X
	Johnson, 2018 ¹¹¹			X						X						X
	Martínez-González, 2018 ¹²⁴												X		X	X
	Légaré, 2018 ¹¹³					X				X			X	X		X
	Baptista, 2018 ¹¹⁷															X
	Spronk, 2018 ¹¹⁸									X					X	X
	Samalin, 2018 ¹²²								X				X		X	X
	Martínez-González, 2018 ¹²³															X
	Martínez-Alonso, 2017 ¹¹²															X
	Stacey D, 2017 ¹¹⁹					X			X							X
	Morrell, 2016 ¹¹⁶														X	X

Type of Strategy	Author, Year	Caregiver-Related Measures	Implementation Measures / Fidelity Elements	Clinical Staff Behavior Change	Cost / Value	Clinician Behavior Change	Provider Satisfaction	System Level Changes	Medication or Self-Management Adherence	Chronic Disease Clinical Outcomes (e.g. A1c, BP)	Patient Reported Outcomes (e.g. Satisfaction and Quality of Life)	Mortality	Quality of Life	Health Care Utilization, Including Re-admissions; overuse of ER	Patient Satisfaction / Experience	Decisional Support Outcome
	Porter, 2016 ¹¹⁵								X	X					X	
	Stovell, 2016 ¹¹⁴								X							X
	Nathan, 2016 ⁹⁹									X					X	X
	van Weert, 2016 ¹⁰⁹								X						X	X
	Friedrichs, 2016 ¹⁰⁷									X					X	X
	Kashaf, 2015 ¹⁰⁶												X			X
	McIntyre, 2015 ¹⁰⁵								X						X	X
	Jain, 2015 ¹⁰⁴															X
	Irizarry, 2015 ¹⁰²						X									X
	Violette, 2015 ¹⁰³									X			X	X		X
	Voruganti, 2017 ⁹⁵									X					X	
	Winston, 2017 ⁹⁸								X	X						X
	Kew, 2017 ⁹⁶								X				X	X	X	
	Clayman, 2015 ⁹⁷								X	X			X			X
Shared Decision Making – Children Only	Malone, 2019 ⁹¹															
	Cheng, 2017 ⁹²															X
	Coyne, 2016 ⁹³															
	Wyatt, 2015 ⁹⁴												X	X	X	X
Transitional Care – Adults Only	Berre, 2017 ¹²⁶											X	X	X		
	Sendall, 2016 ¹²⁵						X						X	X		

Evidence Table 5. Findings of included systematic reviews addressing direct patient care

Type of Strategy	Author, Year	Overall Findings	Strength of Evidence Reported?	Findings	Conclusion Sentence
Advanced Care Planning – Adult Only	Coulter, 2015 ¹	Positive benefit	Yes	Nine studies measured glycated hemoglobin (HbA1c), giving a combined mean difference (MD) between intervention and control of -0.24% (95% confidence interval (CI) -0.35 to -0.14), a small positive effect in favor of personalized care planning	Personalized care planning leads to improvements in certain indicators of physical and psychological health status, and people's capability to self-manage their condition when compared to usual care. The effects are not large
Health Literacy – Adult Only	Schaepe, 2015 ²	Unclear benefit	No	Most articles focused on educational intervention programs for people undergoing PD. Findings on the link between the PD trainer's background and peritonitis rates among individuals undergoing PD are inconsistent. PD learners should be taught self-management	Educational interventions for PD remain an under-researched area, despite the potential they have to make this type of therapy more successful. Further research on education and training for people receiving PD and for PD nurses is needed
Transitional Care – Adult Only	Berre, 2017 ¹²⁶	Positive benefit	Yes	Compared to usual care, significantly better outcomes were observed: a lower mortality at 3 (RD: 0.02 [0.05, 0.00]; NNT: 50), 6, 12 and 18 months post-discharge, a lower rate of ED visits at 3 months (RD: 0.08 [0.15, 0.01]; NNT: 13)	Transitional care for older patients with CD discharged from hospital to home leads to better outcomes in mortality, readmission and readmission days. Decision-makers, managers and clinicians should take these results into account when developing policies
	Sendall, 2016 ¹²⁵	Positive benefit	Yes	this study found intervention patients had lower rehospitalization rates at 30 days (8.3 vs. 11.9, p ¼ 0.048) and at 90 days (16.7 vs. 22.5, p ¼ 0.04) than control patients, and lower hospital costs than intervention patients	This structured review found that community linkages, clinical information sharing, delivery system design, self-management and clinical decision support are common components of a model of care for older people with two or more chronic disease.
Self Management Support – Adult Only	Jacelon, 2016 ⁴⁰	Unclear benefit		The most frequently employed system components were peripheral sensors, feedback on data provided to the individual with the disease, a user diary, provider access to data, provider consultation with the individual who is self managing and web-based education	For individuals to effectively use systems to maintain maximum wellness, the systems must have a strong component of self-management and provide the user with meaningful information regarding their health states.
	Bolscher-Niehuis, 2016 ⁴⁶	Positive benefit	Yes	Although there was considerable variation in study population, intervention characteristics and measurement instruments used, in seven of the 12 included studies (both with a low and high risk of bias)	There is a moderate level of evidence that self-management support programs with a multi-component structure, containing disease-specific information, education of knowledge and skills and, in particular, individually tailored coaching

Type of Strategy	Author, Year	Overall Findings	Strength of Evidence Reported?	Findings	Conclusion Sentence
	Deek, 2016 ⁴⁵	Potential benefit	Yes	Significant reductions in the readmission rates at 30, 90 and 180 days: adjusted odds ratios 0.52 at 30 days 0.43 at 90 days 0.57 at 180 days and a significant prolongation in time to rehospitalization (one study)	Involving the family in self-care has shown improved out- comes in patients with chronic conditions. Coping with a long-term illness may be facilitated when a family caregiver is involved but prospective, systematic and accountable processes are lacking
	Thakkar, 2016 ⁴⁴	Positive benefit	Yes	In the pooled analysis of 2742 patients (median age, 39 years and 50.3% [1380 of 2742] female), text messaging significantly improved medication adherence (odds ratio, 2.11; 95% CI, 1.52-2.93; P < .001). The effect was not sensitive to study characteristics	Mobile phone text messaging approximately doubles the odds of medication adherence. This increase translates into adherence rates improving from 50% (assuming this baseline rate in patients with chronic disease) to 67.8%, or an absolute increase of 17.8%.
	Ha Dinh, 2016 ⁵⁹	Potential benefit	Yes	Four studies confirmed improved disease-specific knowledge in intervention participants. One study showed a statistically significant improvement in adherence to medication and diet among type 2 diabetics patients in the intervention group	Overall, the teach-back method showed positive effects in a wide range of health care outcomes although these were not always statistically significant. Studies in this systematic review revealed improved outcomes in disease-specific knowledge, adherence
	Kim, 2016 ⁴³	Positive benefit	Yes	Of the 30 studies that tested the effect of a CBHW-led intervention on cancer control, 21 studies (70%) found improvements in cancer screening behaviors; Sixteen studies (62%) included in the review found a significant effect of CBHW intervention on CVD	In conclusion, our review of 67 articles shows that CBHWs can be an effective intervention model that is also cost-effective for certain health conditions (e.g., high blood pressure, diabetes) or behaviors (e.g., mammogram and Pap test use)
	Smith, 2017 ⁴¹	Unclear benefit	Yes	Overall the results regarding the effectiveness of interventions were mixed. There were no clear positive improvements in clinical outcomes, health service use, medication adherence, patient-related health behaviors, health professional behaviors	The review suggests that interventions that are designed to target specific risk factors (for example treatment for depression) or interventions that focus on difficulties that people experience with daily functioning (for example, physiotherapy treatment
	Jones, 2015 ⁸⁷	Unclear benefit	Yes	Three studies showed favorable physical activity outcomes following self-management interventions for stroke; however, risk of bias was high, and overall efficacy remains unclear. Although not used in isolation from face-to-face delivery, remote delivery	The efficacy of self-management programs in increasing physical activity levels in community-dwelling adults following acquired brain injury (ABI) is still unknown. Research into the efficacy of self-management programs

Type of Strategy	Author, Year	Overall Findings	Strength of Evidence Reported?	Findings	Conclusion Sentence
	Kuo, 2016 ³³	Potential benefit	no	Evidence from 7 of the 11 included studies suggests significant improvement in patients' hemoglobin A1c (HbA1c) with the use of secure messaging.	Further work must be done to determine how to best maximize the potential of available tools such as secure messaging and EHRs to improve patient outcomes
	Eeden, 2016 ³⁹	Positive benefit	Yes	Eighteen studies found the self-management intervention(s) to be cost-effective compared with other interventions, either due to increased costs and effects in comparison with the control intervention, or decreased costs and increased effects in comparison	Self-management interventions for adult chronic patients were heterogeneous and there was no clear, well-considered definition of self-management. Eighteen studies found the self-management intervention(s) to be cost-effective compared with other interventions
	Palacio, 2016 ³⁸	Positive benefit	Yes	For studies reporting a categorical measure (n = 11), the pooled RR for medication adherence was higher for MI compared with control (1.17; 95 % CI 1.05-1.31; p< 0.01). For studies reporting a continuous measure (n=11), the pooled SMD for medication adherence	MI improves medication adherence at different exposure times and counselors' educational level. However, the evaluation of MI characteristics associated with success had inconsistent results.
	Whitehead, 2016 ²⁵	Potential benefit	Yes	Of the 9 papers we reviewed, 6 of the interventions demonstrated a statistically significant improvement in the primary measure of clinical outcome in mobile apps user. Significant improvements in diabetes-specific clinical outcomes (HbA1c) were reported	The evidence indicates the potential of mobile apps in improving symptom management through self-management interventions. The use of apps in mHealth has the potential to improve health outcomes among those living with chronic diseases
	Yin, 2019 ⁹⁰	Positive benefit	No		Significant benefits have been seen in trials with use of Mobile Health APPs for IBD relating to education, quality of life, quality of care, treatment adherence, and medication management. No studies have reported a negative impact.
	Laukner, 2016 ⁷⁶	Positive benefit	No	Of the nine studies that reported on program outcomes, eight reported positive outcomes with one study reporting mixed results. Overall program success, participants valuing the social aspects of the programs, improved activity or weight loss, and participation	The key findings of this scoping review are as follows: 1. A combination of telecommunications with some face-to-face meetings can support the accessibility of peer support programs in rural areas. 2. Core elements of these programs are the provision of s

Type of Strategy	Author, Year	Overall Findings	Strength of Evidence Reported?	Findings	Conclusion Sentence
	Ammenwerth, 2019 ⁷²	Unclear benefit	No	studies found no or only a small, clinically non-relevant effect of patient portals.	Future research should develop a taxonomy to describe patient portal functionalities to facilitate the aggregation of evidence.
	Lee, 2018 ⁷⁷	Positive benefit	Yes	Of the 12 RCTs reviewed, 10 of the mHealth interventions demonstrated statistically significant improvement in some health outcomes by incorporating mobile applications in managing chronic diseases.	Findings from mHealth intervention studies for chronic disease management have shown promising aspects, particularly in improving self-management and some health outcomes.
	Donald, 2018 ⁷³	Unclear benefit	No	The most common intervention topic was diet/nutrition and interventions were regularly delivered face to face. Interventions were administered by a variety of providers, with nursing professionals the most common health professional group.	We were unable to draw conclusions regarding the most effective self-management intervention for adult patients with chronic kidney disease, keeping in mind that our aim was to review the breadth of the current literature and present the gaps that exist.
	Aquino, 2017 ⁷¹	No benefit	Yes	Five studies (45.5%) showed significant improvements in HbA1c reduction, improvements in self-efficacy (18.2%), knowledge levels of DM (18.2%), quality of life (18.2%). However, after meta-analysis, no statistically significant improvement was found	This systematic review showed that individual strategies for DM empowerment were not effective in reducing HbA1c, despite contributing to improvements in psychosocial parameters. Therefore, individual strategies need to be reviewed so that they become effective
	Kelly, 2018 ⁸³	Unclear benefit	No	Evidence supporting the role of inpatient portals in improving patient and caregiver engagement, knowledge, communication, and care quality and safety is limited. Providers had concerns about using inpatient portals	Further investigation is needed to optimally design inpatient portals to maximize potential benefits or hospitalized patients and caregivers while minimizing unintended consequences for healthcare teams.
	Boulley, 2018 ⁷⁴	Potential benefit	Yes	There was considerable heterogeneity in study methods, in outcome definitions, in measures for engagement with DI and in psychosocial variables assessed. Results from the studies showed a high level of engagement.	The present review showed that despite the heterogeneity in the studies assessed and inconsistent results, DI may constitute an excellent means to help cancer patients and survivors cope better with the disease and with treatment side effects

Type of Strategy	Author, Year	Overall Findings	Strength of Evidence Reported?	Findings	Conclusion Sentence
	Kim, 2015 ²⁶	Positive benefit	Yes	Compared to conventional interventions the web-based interventions provide diverse health information in various forms by providing links to rich information sources. Another unique feature of automated functions of the web-based interventions is the tail	Web-based self-management support interventions for cancer survivors were found to be effective in improving fatigue, depression, anxiety, and overall quality of life, with the benefits of the automated and communicative functions available on the Web
	Dendere, 2019 ⁸¹	Unclear benefit	No	some but not all studies found patient portals improved patient engagement; patients perceived some portal functions as inadequate but others as useful; patients and staff thought portals may improve patient care but could cause anxiety in some patients	While the evidence is currently immature, inpatient portals have demonstrated benefit by enabling the discovery of medical errors, improving adherence to medications, and providing patient-provider communication, etc. High-quality studies are needed
	Peytremann-Bridevaux, 2015 ⁷⁵	Positive benefit	Yes	Compared with usual care, chronic disease management program resulted in improvements in asthma-specific quality of life (SMD 0.22, 95% confidence interval (CI) 0.08 to 0.37), asthma severity scores (SMD 0.18, 95% CI 0.05 to 0.30)	There is moderate to low quality evidence that chronic disease management program for adults with asthma can improve asthma-specific quality of life, asthma severity, and lung function tests. Overall, these results provide encouraging evidence
	Zhao, 2015 ⁵³	No benefit	Yes	The meta-analysis of six eligible studies revealed no significant difference in asthma symptom score change between the telemedicine and control groups (pooled Hedges's $g = 0.34$, 95% confidence interval = -0.05 to 0.74, $Z = 1.69$, $p = 0.090$).	Telemedicine interventions do not appear to improve asthma function scores, but other benefits may be present.
	Kruse, 2015 ⁸⁹	Unclear benefit	No	Very few studies associated use of the patient portal, or its features, to improved outcomes; 37% (10/27) of papers reported improvements in medication adherence, disease awareness, self-management of disease, a decrease of office visits	More studies needed that assess effect of patient portals on patient outcomes quality of care. Few articles analyzed the full patient portal but instead analyzed features of a portal such as secure messaging, as well as disease management and monitoring.
	Hammer, 2015 ⁴²	Potential benefit	No	Overall findings from these in-person educational sessions were positive with an overarching quality of life and/or symptom-driven quality-of-life theme. More definitive findings between specific interventions and focused outcomes were not found	Current interventions that direct patients in self-care management of symptoms and associated challenges with cancer/survivorship are helpful, but incomplete. No one intervention can be recommended over another

Type of Strategy	Author, Year	Overall Findings	Strength of Evidence Reported?	Findings	Conclusion Sentence
	Hamine, 2015 ⁸⁵	Potential benefit	No	Short message service was the most commonly used mAdherence tool in 40.2% (43/107) of studies. Usability, feasibility, and acceptability or patient preferences for mAdherence interventions were assessed in 57.9% (62/107) of studies and found to be general	There is potential for mHealth tools to better facilitate adherence to chronic disease management, but the evidence supporting its current effectiveness is mixed. Further research should focus on understanding and improving how mHealth tools can overcome
	Wildevuur, 2015 ⁸⁶	Potential benefit	No	The type of ICT mostly used by persons with a chronic condition for interacting with health care providers is ICT for self-measurement of the body (n=143) (Table 9); the highest rankings were found in studies on diabetes (n=48) and cardiovascular (n=47)	Persons with a chronic disease could benefit from an ICT-enabled PCC approach, but ICT-PCC also yields organizational paybacks. It could lead to an increase in health care usage, as reported in some studies. Few interventions could be regarded as “fully”
	Price, 2015 ⁷⁰	Positive benefit	No	Diabetes outcomes related to PHR most studied - 11 of the 12 studies in DM showed benefit.	Small body of condition specific evidence that has been published. Conditions with evidence of benefit when using PHRs tended to be chronic conditions with a feedback loop between monitoring in the PHR and direct behaviors that could be self-managed
	Warrington, 2019 ⁷⁸	Unclear benefit	Yes	Only publications that included some data on patient engagement or patient-centered outcomes were included (N=29). A lack of consistency between studies in how engagement was defined, measured, or reported, and a wide range of methods chosen to evaluate	Electronic systems have the potential to help patients manage side effects of cancer treatment, with some evidence to suggest a positive effect on patient-centered outcomes. However, comparison across studies is difficult due to the wide range of assessment
	Nazarov, 2019 ⁵⁵	Positive benefit	Yes	We found that workplace-based interventions can lead to positive changes in employment status, work ability, RTW, and sick leave rates for people with various chronic conditions; Here, four of the seven studies on multidisciplinary interventions reported	We found that workplace-oriented and multidisciplinary programs are the most supportive to RTW and reducing the absence due to illness. In addition, cognitive behavioral therapies achieve positive results on RTW and sick leave.
	Sokol, 2016 ³⁶	Potential benefit	No	Forty-four studies (94%) reported significant changes favoring peer support. Eleven strategies emerged for engaging and retaining hardly reached individuals. Among them, programs that reported a strategy of trust and respect had higher participant retention	Peer support is a broad and robust strategy for reaching groups that health services too often fail to engage. The wide range of audiences and health concerns among which peer support is successful suggests that a basis for its success may be its flexible

Type of Strategy	Author, Year	Overall Findings	Strength of Evidence Reported?	Findings	Conclusion Sentence
	Changizi, 2017 ⁶¹	Positive benefit	No	The mHealth technology can help change and develop health behaviors (increased consumption of fruits and vegetables, stress management, reduced consumption of salt and improved quality of diet and sleep) and improve self- efficacy in elderly individuals	Findings showed that mHealth can improve care, self-management, self-efficacy, behavior promotion (quality of sleep, diet, physical activity mental health) and medication adherence. The mHealth technology has proven effective for disease prevention
	Ko, 2018 ⁶⁰	Unclear benefit	No	This review found that self management has been assessed through prerequisites of self-management and behaviors involved in self-management.	This review revealed that current literature does not operationalize self-management in multiple chronic conditions as a process, indicating incomplete assessments of self-management. Future studies should consider self-management as an iterative process
	Alessa, 2018 ⁴⁷	Potential benefit	Yes	As shown in Table 3, 6/9 (67%) studies demonstrated positive effects on BP; The decrease in the intervention arm ranged from 8.7 to 34.8 mm Hg. Significant decreases in DBP were reported in 2/6 (33%) studies, ranging from 4.9 to 12 mm Hg;	Most of the studies reported that apps might be effective in lowering blood pressure and are accepted by users. However, these findings should be interpreted with caution, as most of the studies had a high risk of bias.
	Skrabal Ross, 2018 ⁵⁸	Unclear benefit	No	The 2 experimental studies in this review (Spoelstra et al's study and Greer's et al's CORA experimental study) did not find statistically significant differences between the experimental and control groups.	Despite the increasing body of evidence on the use of mobile phones to deliver medication adherence— enhancing interventions in chronic diseases, literature on the oral chemotherapy context is lacking.
	Jeddi, 2017 ⁶³	Positive benefit	Yes	The studies assessed 15 outcomes, including eight clinical out- comes and seven process of care outcomes. In 12 (80%) of the 15 outcomes, the studies had revealed the effects of the interventions as statistically significant positive.	This systematic review combined the results of RCTs that evaluated the effect of IT-based interventions on self-management outcomes in CKD patients. The results (eight studies, 1637 patients) showed that IT-based interventions had improved self-management
	Sangrar, 2019 ⁵⁶	Potential benefit	No	The most prominent consideration when designing blended learning patient self-management programs is to ensure that the educational program is suitable for the target population and the individual patient.	This review identified that most research related to chronic disease self-management programs that blend face-to-face educational components with online/computer-based educational components remains at the level of pilot or feasibility studies.

Type of Strategy	Author, Year	Overall Findings	Strength of Evidence Reported?	Findings	Conclusion Sentence
	Conway, 2017 ⁶⁴	Unclear benefit	No	There are positive benefits of the use of one-way and two-way digital health messages to engage patients in timely self-management to improve medication adherence. Strategies such as IVR and SMS text messaging provide evidence of improved short-term	The 13 studies included in this review found no conclusive evidence of improved medication adherence using digital health interventions such as interactive voice response (IVR), short message service (SMS) text messaging, telemonitoring
	Lederle, 2019 ⁵⁴	Potential benefit	No	The meta- analysis showed mixed results, and many of the overall effect sizes were not statistically significant. The participants of a lay-led self-management program had fewer emergency department visits (SMD: -0.08; 95% CI: -0.15 to -0.01; p=0.02)	Although the statistically significant effects of the meta-analysis are low, our overall findings show that only a small number of the included studies tackled the task of comprehensively investigating self-management skills in the context of health care
	Levengood, 2019 ⁵²	Positive benefit	No	Com- pared with usual care, TBC reduced HbA1c levels by an additional 0.5% (95% CI= -0.7, -0.3, I2=84.8%).	The available evidence demonstrates that for patients with diabetes, TBC improves their blood glucose, BP, and lipid levels. TBC interventions also increase the proportion of patients who reach target blood glucose, BP, and lipid levels
	Han, 2019 ⁵¹	Positive benefit	Yes	CHC interventions were generally effective in HbA1c reduction either via individual education, group education or both although insignificant HbA1c reductions were also noted in nine studies . CHC interventions were also effective in improving lipids	CHC interventions are in general effective in promoting glucose control when using face-to-face interactions in low-income, underserved, and racial and ethnic minority patients with diabetes.
	Warner, 2019 ⁵⁰	Potential benefit	Yes	The 31 included studies demonstrated community-based SMP programs actively engaged participants and provided strategies to improve health behavior or care of their condition. Seventy-nine percent of studies reported significant differences	Self Management Programs are not supporting older adults to use strategies to address the impact of conditions on their everyday lives, addressing the needs of older adults with multiple conditions, nor assessing outcomes that align with the strategies
	Luedke, 2019 ⁴⁹	Unclear benefit	Yes	Limited evidence for benefit on selected primary or secondary outcomes. Educational self-management interventions may improve the use of self-management practices, and quality of life may improve with therapy-based self-management approaches.	These self-management interventions showed clinically important benefit for only a limited number of outcomes, but the confidence in these findings was mostly low. Further, there is unexplained variability in the effect of education interventions on quality

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	Debon, 2019 ⁴⁸	Positive benefit	No	The main lifestyle changes were the reduction of body weight, promotion of healthy eating, and adherence to the regular practice of physical exercises. Another significant result is the decrease in blood pressure and glycemic levels.	Technology can facilitate health care with simple messages and alerts that aid in adherence to treatment. Changes in lifestyle with the use of applications are remarkable
	Dounavi, 2019 ⁶⁹	Positive benefit	Yes	mHealth apps can be effective in the self-management of weight, such as in reducing weight, and improving health indicators, such as glucose levels and blood pressure; one study found no significant improvements as a result of using a PDA for self-monitoring	There is sufficient consensus across studies that mHealth apps are acceptable by patients and effective in producing weight loss through lifestyle changes in eating behaviors and physical activity patterns.
	Zhao, 2016 ⁵⁷	Positive benefit	Yes	The pooled main outcomes by random-effects model showed significant improvements in HbA1c, self-efficacy, and diabetes knowledge, but not in BMI. we cannot draw any real conclusions regarding QoL due to heterogeneity.	To get theory-based interventions to produce more effects, the role of patients should be more involved and stronger and the education team should be trained beyond the primary preparation for the self-management education program.
	Sakakibara, 2016 ³⁴	Positive benefit	Yes	The model estimating an effect averaged across all stroke risk factors was not significant, but became significant when four low-quality studies were removed (SMD = 0.10 [95 % CI = 0.02 to 0.17], I ² = 0%, p = 0.01).	Self-management interventions appear to be effective at improving overall risk factor control; however, more high-quality research is needed to corroborate this observation. Self-management has a greater effect on lifestyle behavior risk factors
	Noonan, 2019 ³²	No benefit	Yes	Compared with usual care, there was similar magnitude in mean improvement in patient health-related quality of life with self management interventions in trials involving caregivers (SMD: 0.23, 95% confidence interval: -0.15–0.61)	Within the methodological constraints of this study, our results indicate that involving caregivers in self-management interventions does not result in additional improvement in patient health-related quality of life in heart failure or chronic obstructive
	Plow, 2016 ³¹	Potential benefit	No	Reported intervention effects on health and function included statistically significant improvements across time or between groups in patient-reported physical function (n = 5), fatigue (n = 3), patient-reported mental health (n = 3)	To advance the science of tailoring self-management interventions, we recommend conducting comparative effectiveness research and further developing a taxonomy to standardize descriptions of tailoring.

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	Stenberg, 2016 ³⁰	Positive benefit	Yes	The participants experienced the programs as beneficial according to less symptom distress and greater awareness of their own health, improved self-management strategies, peer support, learning and hope.	A substantial evidence base (Quantitative and Qualitative studies) supports the conclusion that participating in a group based patient education programs aimed at promoting self management in different ways have been experienced as beneficial for the participant
	Hooft, 2016 ²⁹	Potential benefit	Yes	Nurse-led interventions focusing on patients' intrinsic motivation and self-efficacy were most successful. Least successful were interventions providing solely education aimed at changing patients' behavior.	Successful interventions focus on patients' intrinsic processes (i.e. motivation or self-efficacy). This would guide nurses to decide what self-management support intervention they can best use in their specific setting and patient group.
	Kelly, 2018 ⁶²	Unclear benefit	Yes	Primary QOL: Mean SGRQ Total scores in both groups improved over time but were not significantly different at six weeks', three and 12 months' follow-up (6 weeks MD -12.70, 95% CI -30.39 to 4.99; 3 months MD -9.15, 95% CI -28.08 to 9.78; 12 months MD -1	There is inadequate published evidence to guide clinical decisions as to the potential benefits and risks of self-management interventions for people with non-cystic fibrosis bronchiectasis. The evidence was limited by a number of factors
	Teljeur, 2016 ²⁷	Positive benefit	Yes	There was reasonably consistent evidence across 22 studies evaluating education self-management support programs suggesting these interventions are cost-effective or superior to usual care. Telemedicine-type interventions were more expensive than usual	Self-management support education programs may be cost-effective. There was limited evidence regarding other formats of self-management support interventions. The poor quality of many of the studies undermines the evidence base
	Pereira, 2015 ⁸⁸	Positive benefit	No	DSME delivered via the Internet is effective at improving measures of glycemic control and diabetes knowledge compared with usual care (printed written interventions). In addition, results demonstrate that improved eating habits and increased attendance	Internet-delivered diabetes education has the added benefit of easier access for many individuals, and patients can self-pace themselves through materials. More research on the cost-benefits of Internet diabetes education
	Whiteman, 2016 ³⁵	Potential benefit	Yes	Most studies demonstrated feasibility, acceptability, and preliminary effectiveness; however, clinical effectiveness could not be established in most of the studies due to methodological limitations.	Integrated medical and psychiatric illness self-management interventions appear feasible and acceptable, with high potential for clinical effectiveness. However, implementation considerations were rarely considered in intervention development

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	Zomahoun, 2016 ³⁷	Positive benefit	Yes	Interventions that were based on MI only [b ¼ 0.183, 95% CI¼(0.004, 0.362)] or those in which interventionists were coached during intervention implementation [b ¼ 0.465, 95% CI¼(0.028, 0.902)] were the most effective. MI interventions that were delivered	This synthesis of RCTs suggests that pooled MI intervention effect size on medication adherence is positive yet very small. MI interventions might be effective at enhancing of medication adherence in adults treated for chronic diseases
	Massimi, 2017 ⁶⁸	Positive benefit	Yes	Meta-analyses on systolic (SBP) and diastolic (DBP) blood pressure reduction (10 studiesD3,881 patients) and HbA1c reduction (7 studiesD2,669 patients) were carried-out. The pooled MD were: SBP -3.04 (95% CI -5.01D-1.06), DBP -1.42 (95% CI -1.42D-0.49) an	Meta-analyses of subgroups showed, among others, a statistically significant effect if the interventions were delivered to patients with diabetes (SBP) or CVD (DBP), if the nurses were specifically trained, if the studies had a sample size higher than 200
	Clarks Smith, 2017 ⁶⁷	Unclear benefit	Yes	There was uncertainty about the effect of self-monitoring plus education on the percentage of time the INR was within the therapeutic range. Small and positive effects on anxiety and depression in individuals who received education compared to those who r	Patients participating in both educational interventions and self monitoring interventions (with education) appear to spend more time within the therapeutic INR range, but pooled analyses of the AF data did not significantly favor self-monitoring plus education
	Cho, 2017 ⁶⁶	Unclear benefit	Yes	Four studies of technology-mediated interventions resulted in improvement in QoL. Four studies considered QoL as a secondary outcome neutral impact on QoL and one study resulted in a negative. Overall, four studies had a low risk of bias	The evidence to support the improvement of QoL using technology-mediated interventions is insufficient. This lack of research highlights the need for increased study of QoL as an outcome measure and the need for consistent measures
	Kim, 2017 ⁶⁵	Unclear benefit	No	Data from 13 RCTs showed that patients with heart failure and asthma reported improved quality of life in 4 trials, the most frequently reported health improvement was HbA1c control among patients with diabetes in 3 trials	Limitations of current research included a lack of gerontological focus, dominance of preexperimental design, narrow research scope, inadequate support for participants, and insufficient evidence for clinical outcome.
	Hecke, 2016 ²⁸	Unclear benefit	Yes	Two high-quality studies showed inconsistent results regarding reduction of death rates, emergency department admissions and hospitalization. Although with acceptable quality of studies, there is no clear evidence for the effectiveness	Limited evidence was found for self-management support interventions in chronically ill patients with low socio-economic status. Essential characteristics and component(s) of effective self-management support interventions for these patients

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	Risling, 2017 ⁸⁴	Unclear benefit	No	4 of 19 (mostly non quantitative studies) were found to have used specific patient empowerment measures.	Few non-qualitative studies; overall, studies lack of conceptual clarity in patient empowerment research, and this has extended to study within the eHealth context
	Palacios, 2017 ⁷⁹	Potential benefit	Yes	Statistically significant difference/ improvement in intervention group for wt loss, angina symptoms and frequency (2 trials), in dietary outcomes and increased physical activity (5 trials), improved QoL over longer f/up (3 trials), and mood symptoms	Internet-delivered self-management support for improving CHD, well-being and self-management related outcomes is potentially effective, but existing trial evidence is insufficient to draw definitive conclusions. There is a lack of evidence on the impact
Self Management Support – Adults and Children	Barello, 2016 ¹⁴	Unclear benefit	No	On the one hand, we described the main patient engagement outcomes of eHealth interventions; they appear to confirm how internet technologies in healthcare are able to give patients a starring role in their own healthcare.	To sum up, the eHealth interventions reviewed were mainly devoted to foster only one or two experiential dimensions of patient engagement (i.e., alternatively cognitive, emotional or behavioral experiential dimensions related to the healthcare management
	Lancaster, 2018 ¹⁷	Positive benefit	Yes	14 RCTs found statistically significant increases in positive medication changes as a result of using eHealth tools, as did the single open-label study. Moreover, 8 RCTs found improvement in patient symptoms following eHealth tool use, especially in adolescents	Patients generally found eHealth tools useful in improving communication with health care providers. Moreover, health-related outcomes among frequent eHealth tool users improved in comparison with individuals who did not use eHealth tools frequently.
	Lycett, 2018 ¹⁶	Positive benefit	Yes	A total of 3 studies reported a significant positive effect of the intervention on adherence; 3 studies reported a significant positive effect of the intervention on self-management behavior [54], 2 studies reported a significant positive effect on asthma	Our findings suggest that theory-based digital interventions to enhance asthma self-management can be effective at improving adherence and self-management and that more extensive use of theory in the development and application of digital interventions
	Bashi, 2018 ¹⁵	Positive benefit	Yes	4 RCTs showed statistically significant effects of smartphone-based interventions on health outcomes, including the patient engagement level, hemoglobin A , weight loss, and depression while 3 RCTS showed no difference on cardiorespiratory fitness	this review generally support that patients with diverse conditions benefit from mobile-based educational interventions. However, we were unable to identify any effective specific structure or strategy for the delivery of such interventions

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	Niznik, 2018 ¹³	Positive benefit	No	Studies reporting adherence outcomes had an overall positive rate of 62.5% (5 of 8). Studies reporting clinical disease management outcomes had an overall positive rate of 67.8% (19 of 28).	Clinical pharmacy telemedicine interventions in the outpatient or ambulatory setting, primarily via phone, have an overall positive impact on outcomes related to clinical disease management, patient self-management, and adherence
	Kew, 2016 ¹⁸	Unclear benefit	Yes	Evidence from these studies did not show clearly whether asthma telemonitoring with feedback from a healthcare professional increases or decreases the odds of exacerbations that require a course of oral steroids (OR 0.93, 95% confidence Interval (CI) 0).	Current evidence does not support the widespread implementation of telemonitoring with healthcare provider feedback between asthma clinic visits. Studies have not yet proven that additional telemonitoring strategies lead to better symptom control or reduction
	Graham, 2016 ¹⁹	Potential benefit	Yes	In summary, with one exception (Nordin & Rorsman, 2012), ACT interventions were consistently associated with post-intervention improvements (i.e., reductions) in distress. However, bar one highly- supportive but lower-quality study (Rost et al., 2012)	ACT has been applied in many different ways within a range of long-term conditions. However, there have been no trials of ACT for improving medication non-adherence. Most of the included studies were of low quality and there were very few RCTs.
	Kruse, 2015 ²⁴	Unclear benefit	No	Patient portals showed significant improvements in patient self-management of chronic disease and improve the quality of care provided by providers. Patient-provider communication improved in 10 of 27 articles as reported by both patients and providers.	Mixed attitudes from patients and their providers regarding the use of patient portals to manage their chronic disease.
	Chi, 2015 ²¹	Positive benefit	Yes	Sixty-two articles (95%) reported that caregivers had significant improvements in outcomes. The outcomes included enhanced psychological health (less anxiety, depression, stress, burden, irritation and isolation) (44%), higher satisfaction/confidence	The review showed that telehealth tools can enhance care not only to patients but also to family caregivers. As caregivers take care of a loved one, they may benefit from increased and more efficient communication with health care providers or other caregivers
	Pamungkas, 2017 ²³	Positive benefit	No	The combination of didactic with other methods such as participatory learning, goal setting, action planning and problem-solving had a positive impact on health outcomes and improved health behaviors (4 trials).	Overall, family support had a positive impact on healthy diet, increased perceived support, higher self-efficacy, improved psychological well-being and better glycemic control. No meta-analysis done.

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	Yin, 2019 ²⁰	Unclear benefit	No	No findings presented for the self-monitoring or self-management outcomes; Only 3 studies reported the impact of the intervention on health-related measures [12,14]. Specifically, Bächlin [17] found that the intervention had a sensitivity of 73.1%	The emerging nature of the field is reflected in the small number of included studies, their recent time of publication (all after 2010), and the predominance of quasi-experimental study designs. RCTs are needed to evaluate the effectiveness
	Hill, 2015 ²²	Positive benefit	Yes	Fifteen of 16 eligible studies reported a positive intervention effect in at least one outcome. (Improved wt loss, self efficacy, SM, life style change, QoL) There was heterogeneity in terms of health coaching interventions with different methodology	Health coaching is a promising strategy for health improvements; however, future research should ensure clarity in reporting intervention details, clearer definitions of health coaching/theoretical bases, consistency in reporting BCTs
Self Management Support – Children Only	Low, 2019 ⁴	No benefit	Yes	The combined data for meta-analysis of 6 trials showed that there was no statistically significant group difference in quality of life (n=3, standardized mean difference -0.15, 95% CI -0.52 to 0.22; P=.43), self-efficacy (n=3, standardized mean difference)	AYAs were receptive to receiving information through a website or mobile app, which is a first step to engaging them in their own care. Although no conclusion can be drawn on an effective intervention design because of the lack of intervention efficacy
	Saxby, 2018 ⁵	Positive benefit	Yes	The matching of teaching approaches to children's age/ developmental stage was identified as an overarching concept in CCSM educational interventions. It is important that knowledge and skills are taught to the right level of complexity.	Self-management education interventions that are tailored to a child's age/developmental stage help children with asthma, T1DM, and CF to develop effective skills, attitudes, and behaviors to manage their health.
	Knafl, 2017 ⁶	Potential benefit	No	Interventions focusing on family functioning targeted changing family roles, relationships, or processes. In 89% of the interventions, changes in these areas were linked to improved condition control, adherence, or child well-being.	Investigators most often sought to improve condition control or management, with parent engagement focused on improving capacity to manage the treatment regimen. Few investigators addressed capacity building in the context of family functioning.
	Clemente, 2016 ¹²	Potential benefit	Yes	The "Growing up and moving on" program achieved improvements in health-related quality of life, arthritis- related knowledge and satisfaction with rheumatology care in both adolescents and parents, and in vocational readiness markers	We have found several common core features amongst the evaluated programs. Firstly, a written transition policy, that incorporates the views of the pediatric and adult team, as well as the wider multidisciplinary team as appropriate.

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	Campbell, 2016 ⁷	Unclear benefit	Yes	There were positive outcomes in the patients' knowledge of their condition following a nurse-led, one-on-one intervention. The results also suggested that interventions that use technology may have a beneficial effect on participants' self-efficacy	The available evidence (four small studies; N = 238), covers a limited range of interventions developed to facilitate transition in a limited number of clinical conditions, with only four to 12 months follow-up.
	Bal, 2015 ³	Potential benefit	Yes	Our findings suggests that pediatric SMI might be effective at influencing disease knowledge, adherence, but not at symptom severity and school attendance. Conflicting evidence was found for effectiveness of SMI on dealing with the chronic condition	Adherence could be improved through interventions focused on medical management, provided individually in a clinical or home setting by a mono-disciplinary team. Interventions focused on dealing with a chronic condition might be provided individually
	Majeed-Ariss, 2015 ⁸	Unclear benefit	Yes	The one study that was a randomized controlled trial did not report any quantitative results as only 3 of the 4 participants completed the trial. Cafazzo et al reported means and standard deviations before and after their intervention	A key finding of the review is the paucity of evidence-based apps that exist, in contrast to the thousands of apps available on the app market that are not evidence-based or user or professional informed.
	Charlier, 2015 ⁹	Potential benefit	Yes	Two studies reported significantly better self-management in the game group than in the control group after the intervention. For self-management, pooled estimate of Hedges' g was 0.310 (95% confidence intervals, 0.122-0.497)	Two studies reported significantly better self-management in the game group than in the control group after the intervention. Our meta-analysis showed that educational video games are effective in improving knowledge and self-management of young persons
	Sattoe, 2015 ¹⁰	Unclear benefit	No	This review revealed that most interventions for young people represented in the literature solely aim at medical management, like interventions for adults. Six self-management skills match the tasks of medical, role and emotion management	SMI relate to self-management tasks and skill-building. Yet, conceptualizations of self-management support often remained unclear and content focuses predominantly on the medical domain, neglecting psychosocial challenges for chronically ill young people
	Hamline, 2018 ¹¹	Positive benefit	Yes	The overall risk ratio of readmissions for studies in which an FEI alone was conducted was 0.78 (95% CI: 0.63–0.97; I ² = 66%; Supplemental Fig 3, Table 3). Overall, 43% of FEI studies (13 of 30) were associated with reduced readmissions.	Specifically, the meta-analysis revealed that pooling of CCI and FEI in both chronically ill and neonatal patient populations was associated with a decrease in readmissions, whereas single-category interventions alone did not decrease readmissions.

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	Almutairi, 2019 ⁸²	Positive benefit	No	Seven intervention demonstrated a significant reduction in HbA1c, ranged from 0.36 to 0.80%. All interventions presented an improvement in at least one self-management behavior.	Patient activation intervention showed a significant positive effect on T2DM glycemic control and SMBs, particularly physical activity, healthy diet, foot care and blood glucose self-monitoring.
	Warner, 2015 ⁸⁰	Potential benefit	Yes	Six of the nine studies assessed participation in everyday life activities or functional ability, two of the six demonstrated statistically significant differences between the self-management interventions and the controls over time in stroke patients.	There are indications that self-management programs in stroke patients can significantly increase participation and functional ability. However, the high level of clinical heterogeneity in program delivery, outcomes and level of stroke severity
Shared Decision Making – Adults Only	Kashaf, 2017 ¹²¹	Positive benefit	Yes	Same as conclusion	We found substantial evidence of an association between SDM and improved decision quality, patient knowledge and patient risk perception. We found little evidence of an association between SDM and glycemic control, patient satisfaction, quality of life
	Légaré, 2018 ¹¹³	Unclear benefit	Yes	It is uncertain if interventions targeting patients when compared with usual care increase SDM whether measured by observation or reported by patients, reduce decision regret, improve physical or mental health-related quality of life, affect consultation	It is uncertain whether any interventions for increasing the use of SDM by healthcare professionals are effective because the certainty of the evidence is low or very low.
	Martínez-González, 2018 ¹²⁴	No benefit	Yes	SDM improved knowledge (SMD 0.23, 95%CI 0.02 to 0.43; 2 RCTs), but was not different to usual care in reducing either patient participation in prostate-specific antigen (PSA) testing (RR 1.03, 95%CI 0.90 to 1.19; 2 RCTs) or decisional conflict	There is currently insufficient evidence to support a clear association of SDM on patient- and SDM related outcomes for decisions about PSA testing. Further research needs to assess the clinical effectiveness of SDM using well-defined SDM interventions
	Johnson, 2018 ¹¹¹	Unclear benefit	Yes	Four studies, none at low risk of bias, reported a measure of shared decision making; the intervention increased shared decision making in one study. Four studies reported blood pressure between 6 months and 3 years after the intervention	Despite widespread calls for shared decision making to be embedded in health care, there is little evidence to inform shared decision making for hypertension, one of the most common conditions managed in primary care.

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	Berlin, 2018 ¹¹⁰	Positive benefit	Yes	Studies suggest that DAs reduce patient-reported decisional conflict (MD, -4.55 [95% CI, -8.65 to -0.45], P = 0.03 in the fixed-effects model and MD, -4.70 [95% CI, -10.75 to 1.34], P = 0.13 in the random-effects model).	The existing literature suggests that DAs reduce decisional conflict, improve self-reported satisfaction with information, and improve perceived involvement in the decision-making process for women considering breast reconstruction.
	Baik, 2018 ¹⁰⁸	Unclear benefit	Yes	Across studies, there were inconsistent findings about whether the SDM intervention improved patient/caregiver outcomes. The quality of the studies was modest and technology-enabled delivery modes (e.g., video, DVD, web-based tool) were most commonly used	The findings from the studies that examined the effects of the SDM intervention on patient outcomes were inconsistent, highlighting the need for further SDM intervention studies among diverse patient populations using consistent measures.
	Wagner, 2019 ¹⁰⁰	Unclear benefit	Yes	The results from the studies on patient education showed a significant increase in patient activation. Ten studies showed statistically significant and, in part, clinically relevant improvements in the target parameters following the intervention.	The differences found in the studies made it difficult to compare the interventions and the results. There is a need for studies that systematically evaluate and further develop interventions in this area to promote shared decision-making.
	Vermunt, 2017 ¹²⁰	Positive benefit	Yes	The four multifactorial interventions (Guided Care Program for Family and Friends, Guided Care for patients and Helping Older People Experience Success) had significant effects on the application of goal setting, the number of advance directives	A specific focus on collaborative goal setting and/or priority setting was mostly found in a multifactorial intervention, which seems to improve the application of goal setting and the numbers of agreed upon goals and advance directives.
	Goodridge, 2019 ¹⁰¹	Potential benefit	No	Qualitative synthesis: 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%)	The majority of studies to build capacity for participation in care report one or more positive outcomes, although a more comprehensive analysis is warranted.
	Porter, 2016 ¹¹⁵	Unclear benefit	Yes	There was significantly greater improvement in HbA1c in the intervention group compared to the control group in four of the nine studies; Due to the multiple and varied components of the intervention and usual care	It is notable that in all four studies where there were significant benefits for HbA1c, the intervention involved providing the patient with analysis and/or feedback from a clinician on data captured.

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	McIntyre, 2015 ¹⁰⁵	Potential benefit	No	Results are conflicting. Although CBLSSs scored highly in certain outcomes, standard education was more suited to some patient characteristics. Additionally, subgroups of society (older and low socioeconomic populations) were poorly represented in studies.	Up-to-date research on cancer patient education is lacking. CBLSSs proved to be beneficial across the outcomes of knowledge, satisfaction, and decision making and also showed promise for tailoring of information in some cancer populations.
	Jain, 2015 ¹⁰⁴	Potential benefit	Yes	Low-quality evidence suggests that patients who use a video decision aid are less likely to indicate a preference for cardiopulmonary resuscitation (pooled risk ratio, 0.50 (95% CI 0.27 to 0.95); I ² =65%).	Video decision aids may improve some ACP-related outcomes. Before recommending their use in clinical practice, more evidence is needed to confirm these findings and to evaluate the impact of video decision aids when integrated into patient care.
	Irizarry, 2015 ¹⁰²	Unclear benefit	no	research shows mixed results leading researchers to believe that the relationship between SM and utilization is more complex than the simple substitution of online for in-person care suggests.	Health care delivery factors, mainly provider endorsement and patient portal usability also contribute to patient's ability to engage through and with the patient portal. Future directions of research should focus on identifying specific populations
	Violette, 2015 ¹⁰³	Unclear benefit	Yes	Two trials out of 14 suggested a modest positive impact on decisional regret. Results across studies varied widely for decisional conflict (4 studies), satisfaction with decision (2 studies), and knowledge (2 studies).	scant evidence at high risk of bias suggests the variable impact of existing decision aids on a limited set of decisional processes and outcomes. Because current decision aids provide information but do not directly facilitate shared decision making
	Friedrichs, 2016 ¹⁰⁷	Potential benefit	Yes	Two studies found that patients with SUD preferred to be actively involved in treatment decisions. Treatment preferences were assessed in n = 18 studies, where the majority of patients preferred outpatient compared with inpatient treatment.	Given the evidence and recommendations of existing guidelines (e.g. Nice guidelines [5] or the German guideline for screening, diagnosis and treatment of alcohol-related disorders [25]) as well as legislation [3,4]
	van Weert, 2016 ¹⁰⁹	Potential benefit	Yes	This review shows promising results on the effectiveness of decision aids for older adults. Decision aids have the potential to increase older adults' risk perception, improve knowledge, decrease decisional conflict, and improve patient participation	This review shows promising results on the effectiveness of decision aids for older adults. Decision aids improve older adults' knowledge, increase their risk perception, decrease decisional conflict and seem to enhance participation in SDM.

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	Baptista, 2018 ¹¹⁷	Potential benefit	Yes	Compared to usual care, Web-based decision aids increased knowledge (SMD 0.46; 95% CI 0.18-0.75), reduced decisional conflict (MD – 7.07%; 95% CI –9.44 to –4.71), and reduced the practitioner control role in the decision-making process (RR 0.50; 95% CI 0.3	According to this analysis, Web-based decision aids performed similarly to alternative formats (ie, printed, video) for the assessed decision-quality outcomes. The low cost, readiness, availability, and anonymity of the Web can be an advantage
	Stovell, 2016 ¹¹⁴	Potential benefit	Yes	Small beneficial effects of increased shared decision-making were found on indices of treatment related empowerment (6 RCTs; g = 0.30, 95% CI 0.09–0.51), although the effect was smaller if trials with 425% missing data were excluded.	For people with psychosis the implementation of shared treatment decision-making appears to have small beneficial effects on indices of treatment-related empowerment, but more direct evidence is required.
	Kashaf, 2015 ¹⁰⁶	Potential benefit	Yes	The review found weak, but suggestive, evidence for a positive association between perceived patient involvement in decision making, a central dimension of SDM, and QOL outcomes in cancer. No evidence for an inverse association between SDM and QOL.	There is weak evidence that aspects of shared decision-making approaches are positively associated with QOL outcomes and very little evidence of a negative association. The extant literature largely assessed patient involvement, only capturing one aspect
	Morrell, 2016 ¹¹⁶	Positive benefit	Yes	Current low-level evidence suggests that DAs at the end of life are generally acceptable by users, and appear to increase knowledge and reduce decisional conflict, so their refinement and use in routine practice to better document advance care planning	Compared with other ill-health situations, there is a shortage of decision aids for End of Life treatment involving initiation or discontinuation. Overall the available decision aids seemed to enhance patients or surrogate decision-makers' knowledge
	Stacey D, 2017 ¹¹⁹	Positive benefit	Yes	Compared to usual care, decision aids decreased decisional conflict related to feeling uninformed (MD –9.28/100; 95% CI –12.20 to –6.36; 27 studies; N = 5707; high-quality evidence), indecision about personal values (MD –8.81/100; 95% CI –11.99 to –5.63;	Compared to usual care across a wide variety of decision contexts, people exposed to decision aids feel more knowledgeable, better informed, and clearer about their values, and they probably have a more active role in decision making
	Martínez-Alonso, 2017 ¹¹²	Potential benefit	Yes	The use of DAs increased the proportion of women making an informed decision by 14%, 95% CI (2% to 27%) and the proportion of women with adequate knowledge by 12%, 95% CI (7% to 16%). We observed heterogeneity among the studies in confidence in the decision	Tools to aid decision making in screening for breast cancer improve knowledge and promote informed decision; however, we found divergent results on decisional conflict and confidence in the decision. Under the current paradigm change

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	Martínez-González, 2018 ¹²³	Unclear benefit	No		There is significant variation in the extent of SDM implementation among studies addressing SDM for prostate cancer screening and treatment. Further evaluation of these results on patient outcomes
	Samalin, 2018 ¹²²	Positive benefit	No	Selected 3 RCTs showed that the intervention effectively improved patient satisfaction and engagement in the decision-making process in patients with depression. Only one study in patients with bipolar disorder (BD) showed improvement of depressive symptoms	SDM interventions using decision aids and collaborative care showed evidence of improvements in the management of depression. Stronger evidence of SDM interest in BD is needed.
	Spronk, 2018 ¹¹⁸	Potential benefit	Yes	Tools were mainly applicable across the care process, and usable for decisions on supportive care with or without chemotherapy. All tools were designed for patients to be used before a consultation with the physician.	Despite its recognized importance, only two tools were positively evaluated on effectiveness and are available to support patients with metastatic breast cancer in SDM. These tools show promising results in pilot studies and focus on different aspects
	Nathan, 2016 ⁹⁹	Positive benefit	Yes	Most of the trials studied racial (78 %) or ethnic (17 %) minorities with only one trial focused on sexual minorities and none on gender minorities. Ten studies tailored their interventions for their minority populations.	DAs have been effective in improving patient-doctor communication and decision quality outcomes in minority populations and could help address health disparities. However, the existing literature is almost non-existent for sexual and gender minorities
Shared Decision Making – Adults and Children	Clayman, 2015 ⁹⁷	Positive benefit	Yes	Interventions increased patient involvement in 10 (91%) of the 11 RCTs. At least one positive outcome was detected in 5 (50%) of the 10 RCTs reporting increased participation; the ratio of positive results among all outcome variables measured	Very few RCTs in the field have measures of participation in decision making and at least one health outcome. Moreover, extant studies exhibit little consistency in measurement of these variables, and results are mixed.
	Kew, 2017 ⁹⁶	Potential benefit	Yes	Because these studies were conducted in different ways, we were unable to combine their findings. We found evidence from individual studies indicating that shared decision-making may improve quality of life, inhaler adherence and asthma control	Substantial differences between the four included RCTs indicate that we cannot provide meaningful overall conclusions. Individual studies demonstrated some benefits of SDM over control, in terms of quality of life; patient and parent satisfaction; adherence

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	Winston, 2017 ⁹⁸	Potential benefit	No	The most common decisions addressed were cancer screening, risk reduction, advance care planning, and adherence to provider recommendations. Most studies had sample sizes of fewer than 300, and most were performed in the United State.	Video based patient decision aids are largely a positive addition to the traditional process of health care provision. They are used primarily to assist patients in making an informed decision about screening, to promote adherence to medical recommendation
	Voruganti, 2017 ⁹⁵	Positive benefit	No	These tools were predominantly accessed from websites as opposed to Internet-linked native apps and mainly functioned as part of a multifunction platform such as patient-facing portals. Few tools enabled patients to communicate with multiple health care professionals	Web-based tools for text-based patient-provider communication were identified from a wide variety of clinical contexts and with varied functionality. Tools were most prevalent in contexts where intended use was self-management.
Shared Decision Making – Children Only	Malone, 2019 ⁹¹	Unclear benefit			
	Cheng, 2017 ⁹²	Positive benefit	Yes	Of the records included in this review, 12 were aimed at parents, eight were aimed at children or young people, and two were aimed at both parents and young people. Approaches that scored higher on the quality assessment frame- work tended to be decision	Despite these limitations, evidence from the present review suggests that six different approaches are being implemented to facilitate SDM in child and youth mental health. These consist of therapeutic techniques, decision aids, psychoeducational information
	Coyne, 2016 ⁹³	Unclear benefit			
	Wyatt, 2015 ⁹⁴	Potential benefit	Yes	Heterogeneity across studies was high. Meta-analysis revealed SDM interventions significantly improved knowledge (standardized mean difference [SMD] 1.21, 95% confidence interval [CI] 0.26 to 2.17, P 1/4 .01) and reduced decisional conflict	A limited evidence base suggests that pediatric SDM interventions improve knowledge and decisional conflict, but their impact on other outcomes is unclear. The research enterprise to promote SDM has left children behind.

Healthcare Organization and Systems

Evidence Table 1. Study characteristics of included systematic reviews addressing healthcare organization and systems

Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
Oldfield, 2017 ¹²⁷	To characterize the impact of PFACs on health systems	1946-2016	"involved an organization of patients, family members, or community members (possibly including clinicians or hospital staff) that advised a health care system on the level of direct care, organizational design and quality improvement, policy-making, or research, but did not require the term PFAC"; had a comparison group, including RTC, parallel cohort, or historical control	No comparison group; Not in English	Total: 18 (16 unique) RCTs:5 Other: 7 cohort, 1 case study with pre-post evaluations, 3 cross-sectional	Multiple including: Canadian Health and Social Services Centers, US primary health care centers , US Health Systems Agencies, European hospitals, US state newborn screening programs, others not specified
Sharma, 2019 ¹²⁸	To investigate whether patient engagement in patient advisory councils is linked to improvement in clinical quality, patient safety, or patient satisfaction	2002-2015	patient input on an advisory council, board, or committee in any healthcare settings, written in English, activities address organization/system-level changes, including assessment of impact	Patient engagement within their own individual care, patient engagement within research studies, any studies not meeting inclusion criteria	Total: 32 RCTs:1 Other: Quasi-experimental:4 Qualitative: 9 Case studies: 16 Other designs: 2	Not well described
McCarron, 2018 ¹²⁹	To understand how health systems are intentionally investing in the training and skill development of patients and family members	2000-2016	Studies were included if they (1) had an adult patient/Studies were included if they (1) had an adult patient/ consumer focus, (2) contained a description of an investment, (3) focused on programs/activities/events that were determined to have an impact on the participation of patients in healthcare, (4) showcased how patients/ consumers engaged with other patients or the health system, and (5) incorporated investments that enable patients/consumers to participate in various healthcare roles.	Studies were excluded if they (1) focused on in- vestments to improve self-care; (2) did not involve or engage patients; (3) focused on children, animals, or family members; (4) did not report outcomes; or (5) were opinion pieces or letters to the editor.	Total: 15 RCTs:1 Other: 9 qualitative; 3 mixed methods; 2 quantitative non-randomized designs	Not well described

Author, Year	Objective of Review	Literature Start – End Year	Inclusion Criteria	Exclusion Criteria	Number of Included Studies	Settings
Bombard, 2018 ¹³⁰	To identify effective strategies for engaging patients in the design or delivery of health care and the contextual factors enabling their outcomes	1990-2016	Empirical articles that explicitly investigated the participation of patients, caregivers, or families in the design, delivery, and evaluation of health services	Did not explicitly address patient engagement, did not pertain to the design, delivery, or evaluation of health services, did not describe outcomes of engagement, or outcomes did not measure impact on design, delivery, or evaluation of health services	Total: 48 Other: 27 qualitative; 3 quantitative; 13 mixed methods; 5 user panels or advisory meetings	No restriction
Liang, 2018 ¹³¹	To describe patient engagement in hospital health service improvement	2006-2016	Published original studies on engagement of adult patients or providers in hospital health service improvement activities; English language	Studies not based in hospitals; providers not hospital based; more than half of providers were trainees; engagement of children, youth, or their surrogates	Total: 10 Other: 7 qualitative; 3 cross-sectional	Hospital

Evidence Table 2. Population characteristics of included systematic reviews addressing healthcare organization and systems

Author, Year	Study Populations	Medical Conditions
Oldfield, 2017 ¹²⁷	Patients (Adult only); Family care givers; Health care providers; Community members	Diabetes Cancer or cancer screening Mental health Neonatal mortality, newborn screening Ranking of health concerns and priority setting, not specified for a specific disease Development of a research volunteer registry Recommendations for clinical practice guidelines Others not specified
Sharma, 2019 ¹²⁸	Patients (Adult only); Health care providers; Community members, not specified	Asthma Blood pressure, not disease specific (e.g., altered visiting hours) Not specified
McCarron, 2018 ¹²⁹	Patients (age not specified); "Consumers"	Cancer or cancer screening Mental health Pharmacy, not specified
Bombard, 2018 ¹³⁰	Patients (Adults and Children); Family care givers	Diabetes Cancer or cancer screening Mental health Neurologic conditions General health Pediatric or maternity care Emergency or acute care Substance abuse Disability
Liang, 2018 ¹³¹	Patients (Adult only); Family care givers; Health care providers; Well members of the public	Not specified

Evidence Table 3. Intervention characteristics of included systematic reviews addressing healthcare organization and systems

Author, Year	Intervention Focus	Description of Intervention	Strategies
Oldfield, 2017 ¹²⁷	Direct care (three studies) - care strategies or educational materials, disease specific practice guidelines; Organizational design (three studies) - diabetes centers, pediatric clinic for families with limited English proficiency, primary care clinics; Policy-making (five studies); Research (five studies) - four in recruitment and retention of research participants among marginalized populations	"an organization of patients, family members, or community members (possibly including clinicians or hospital staff) that advised a health care system on the level of direct care, organizational design and quality improvement, policy-making, or research"	Groups that involved patients, family members, or community members only Groups that engaged staff or clinicians in addition to patients, family members, or community members
Sharma, 2019 ¹²⁸	Health promotion - colon cancer screening, asthma and blood pressure management; Patient safety; Patient satisfaction	"a group of patients or consumers working with healthcare staff in order to provide input on healthcare services or delivery"	Community Advisory council, community focus groups, town halls
McCarron, 2018 ¹²⁹	Enhanced care or service delivery; Development of specific policy or planning documents; Enhanced governance; Education or tool development		Forums, Patient instructors, Workshops, Co-design
Bombard, 2018 ¹³⁰	Patient engagement in the design, delivery, and evaluation of health services		Consultative activities (i.e., where patients provided input on research design or measures as part of the research or administrative team); "Co-design (i.e., deliberative, reflexive processes where patients and providers work together to create solutions)"
Liang, 2018 ¹³¹	Hospital service improvement		"Consultation activities: questionnaires, interviews, mass media and suggestion boxes;" "Involvement activities: members of standing committees, advisory bodies, project teams or providing education to other patients;" Partnership: citizen advisory panel

Evidence Table 4. Outcomes of included systematic reviews addressing healthcare organization and systems

Author, Year	Intermediate Outcomes	Patient Outcomes
Oldfield, 2017 ¹²⁷	Organizational priority setting Implementation of quality improvement Recruitment/retention of research subjects Conduct of research Direct care services Clinical outcomes Recruitment strategies	Clinical outcomes Recruitment strategies
Sharma, 2019 ¹²⁸	Clinical care - increased intention to engage in colorectal cancer screening, increased use of inhalers and asthma action plans, improved blood pressure control rates Patient safety - 1 report of multiple case studies. One case report attributed 62% reduction in medical errors to redesign including patient advisors Patient satisfaction - 4 papers with "case based results" - "patient advisory councils had a role in affecting patient satisfaction."	
McCarron, 2018 ¹²⁹	Study themes - strategies for engagement Patient engagement in healthcare decision making	
Bombard, 2018 ¹³⁰	Strategies for optimal patient engagement Outcomes of engaging patients Patients' experiences of being engaged	
Liang, 2018 ¹³¹	Extent of patient engagement Determinants of engagement Interventions to increase patient engagement Impact	

Evidence Table 5. Findings of included systematic reviews addressing healthcare organization and systems

Author, Year	Overall Findings	Findings	Recommendations	Conclusion Sentence
Oldfield, 2017 ¹²⁷	Unclear benefit	<p>Impact: "In person deliberation with health system leadership was most effective, and studies that involved patient engagement in research focused on increasing study participation but not in research design or the dissemination of research findings. Programs varied in: structural makeup, terminology used to describe organizations and their components, strategies of recruitment of individuals, and types of outcomes measured. All studies suggested important benefits of community engagement to health systems and research, but some described drawbacks, including greater costs, longer time to achieve consensus among groups, and the generation of lower quality plans when patients are involved." "In-person and collective deliberation, particularly in community-based settings (such as community organizations), is more effective than using mailed surveys or telephone calls, or one-on-one meetings. ...patients with greater community credibility, such as leaders of community organizations, are more effective participants in PFACs than those without."</p> <p>Other: Recruitment: by clinical/administrative staff, recruited by community outreach, elected, and unknown</p>	Standardized tools for measuring engagement; Transparency in and evaluation of recruiting of PFAC members, trainings for communities members without leadership experience	PFACs engage communities through individual projects but evidence of their impact on outcomes is lacking. A paucity of randomized controlled trials or high-quality observational studies guide strategies for engagement through PFACs. Standardized measurement tools for engagement are needed. Strategies for PFAC recruitment should be investigated and reported.
Sharma, 2019 ¹²⁸	Unclear benefit	<p>Impact: "We did not find any rigorous, prospective RCTs that assessed our primary outcomes of patient clinical care, patient safety, or patient satisfaction...We found one cluster randomized trial showing patient advisors helped clinics set priorities that were better aligned with the PCMH and chronic care model." "The few experimental studies did show improvements in some clinical care metrics, clinic priorities, and staff awareness of patient engagement; however, more concrete outcome measures were lacking."</p>		"Five included studies demonstrate promising methods for evaluating patient engagement in healthcare delivery and describe impacts on clinical outcomes and priority setting. Based on the case studies found, patient advisors tend to contribute to patient-facing services that may affect clinical care but are not easily evaluated. As clinics and hospitals implement patient advisory councils, rigorous evaluation of their programs is needed to support the expansion of system-level patient engagement."

Author, Year	Overall Findings	Findings	Recommendations	Conclusion Sentence
McCarron, 2018 ¹²⁹	Unclear benefit	Impact: While significant research exists that highlights how health systems are working with patients to better manage their own care, studies that explore other dimensions of patient engagement are largely absent.		"An evidence base around programs to advance patient engagement is largely absent. An opportunity exists for further research to identify strategies and measures to support patient engagement in healthcare decision-making. "
Bombard, 2018 ¹³⁰	Possible benefit	Impact: Most studies noted more than one type of outcome on the quality of care, including enhanced care or service delivery, development of specific policy or planning documents, and enhanced governance and education or tool development. Engaging patients can also change the culture of staff and care settings. Barriers: Thematically grouped barriers to (1) design (e.g., lack of role clarity), (2) recruitment (e.g., bias in selection), (3) involvement, (4) context (e.g., provider skepticism), and (5) leadership actions.		"Patient engagement can inform patient and provider education and policies, as well as enhance service delivery and governance. Additional evidence is needed to understand patients' experiences of the engagement process and whether these outcomes translate into improved quality of care."
Liang, 2018 ¹³¹	Unclear benefit	Impact: "Only one study evaluated how patient engagement impacted hospital services and no study evaluated the impact of patient engagement on clinical outcomes." Barriers: "Barriers to patient engagement were primarily at the provider level including negative beliefs and attitudes about patient roles and input, lack of knowledge and skills, provider dysfunction and hierarchies, and uncertainty about how to resolve differences between patient and senior management priorities." Other: Extent of patient engagement: "Patient input and influence on decisions was minimal."		"Given the important role of PE in improving hospital services and the paucity of research on this topic, future research should develop and evaluate behavioural interventions for PE directed at patients and providers informed by the PE barriers and facilitators identified here. Future studies should also assess the impact on various individual and organisational outcomes."

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Appendix C. Summary Table for Gray Literature Search

Summary table of patient and family engagement strategies found in the gray literature

Strategy/Resources	Description of Strategy	Evidence/Implementation
Institute for Healthcare Improvement (IHI) Patient Activation http://www.ihi.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx	Ask Me 3® is an educational tool, designed by health literacy experts consisting of 3 questions, that encourages patients and families to ask their providers about their health condition and have better communication with their providers. 1. What is my main problem? 2. What do I need to do? 3. Why is it important for me to do this?	Tested through few pretest–posttest studies. Low significant effect or mixed results on patient activation, patient satisfaction and medication reconciliation. https://www.dhs.wisconsin.gov/library/P-00867.htm https://www.ncbi.nlm.nih.gov/pubmed/19019809 https://www.ncbi.nlm.nih.gov/pubmed/20586368
Institute for Healthcare Improvement (IHI) Patient-administered self-care http://www.ihi.org/resources/Pages/Publications/Teaching-Patients-to-Administer-Their-Own-Care.aspx http://www.ihi.org/resources/Pages/Publications/Patient-Administered-Self-Care.aspx	A 90-day innovation project evaluating the two primary approaches to patient-administered self-care i-e at healthcare facility and at home and the experiences of two healthcare settings with implementing self-care for dialysis and intravenous antibiotics. Four components of a successful patient-administered self-care system. 1. Activated, capable patient and/or caregiver 2. Protocolized procedures 3. Supportive health care system 4. Practitioners trained in patient-administered self-care.	“When comparing the 944 patients in the at-home self-care program to 224 patients who received traditional in-hospital IV antibiotics, the home-based self-care patients had a 47 percent lower readmission rate and a statistically similar mortality rate.”
Institute for Healthcare Improvement (IHI) Family/Care giver support http://www.ihi.org/resources/Pages/Publications/Supporting-Supporters-What-Family-Caregivers-Need-Cancer-Care.aspx	Supporting the Supporters: What Family Caregivers Need to Care for a Loved One with Cancer (Recommendation/education material) Four-part framework for supporting family caregivers: (1) Assess caregivers' needs using formal measures, just as the cancer patient's own needs are assessed. (2) Educate caregivers for their caregiving roles, most notably, with training in the low-level medical support that cancer patients require at home. (3) Empower caregivers to become full-fledged members of the patient's cancer team, all working toward common goals. (4) Assist caregivers proactively in their duties, so that they retain a sense of control and self-efficacy rather than having to react to imminent medical crises without sufficient resources at their disposal.	

Strategy/Resources	Description of Strategy	Evidence/Implementation
Institute for Healthcare Improvement (IHI) ACP/End of life care http://www.ihl.org/resources/Pages/IHIWhitePapers/ConversationReadyEndofLifeCare.aspx	"Conversation Ready": A Framework for Improving End- of-Life Care IHI's "Conversation Ready" approach to help health care organizations and clinicians provide respectful end-of-life care that is concordant with patients' stated goals, values, and preferences and defines five interconnected Conversation Ready principles.	
Institute for Healthcare Improvement (IHI) Patient education http://lippincottolutions.lww.com/blog.entry.html/2017/08/22/5_strategies_forpro-kDDq.html	5 Strategies for Providing Effective Patient Education This web article describes five strategies for success in patient education and engagement. 1. Use of Technology 2. Determine the patient's learning style. 3. Stimulate the patient's interest 4. Consider the patient's limitations and strengths 5. Include family members in patient care.	
Planetree International Patient Activation and Engagement https://resources.planetree.org/50-ways-to-be-an-engaged-patient-2/	50 Ways to be an Engaged Patient. A resource for patients and families. A list of specific actions and behaviors patients and family members can adopt to be more active participants in their healthcare.	
Planetree International 6 Steps to Creating a Culture of Person and Family Engagement in Healthcare. https://resources.planetree.org/6-steps-to-creating-a-culture-of-person-and-family-engagement-in-health-care/	"This toolkit provides guidance to physician practices on creating a practice culture that emphasizes and incorporates the patient and family perspective in every aspect of care, to ultimately improve quality of care"	
Planetree International Patient Activation and Engagement https://resources.planetree.org/questions-to-ask-your-doctor-about-person-centered-care/	Questions to Ask Your Doctor About Person-Centered Care "12 questions framework patients and family members can ask their doctor to better understand opportunities for partnership."	
Open Notes OpenNotes - Patient portals/EHR	OpenNotes is an international movement and platform for patients and Healthcare providers committed to spreading the availability of open visit notes and studying the effects.	Multiple studies showing significant positive impact on patient centered outcomes and engagement.

Strategy/Resources	Description of Strategy	Evidence/Implementation
<p>Institute for Patient- and Family-Centered Care (IPFCC)</p> <p>Individual and Family Engagement in the Medicaid Population</p> <p>https://www.ipfcc.org/bestpractices/Individual-Engagement.pdf</p>	<p>Literature review and key interviews</p> <p>4 broad recommendation categories:</p> <ol style="list-style-type: none"> 1. Advance Individual and Family Engagement Best Practices as a Strategic Priority Within the Medicaid Agency 2. Expand Opportunities for Individuals and Families to Engage with Medicaid Staff and Managed Care Entities to Influence Policies, Programs, and Practices. 3. Support Direct Care Service Providers in Acquiring the Knowledge and Skills to Develop Effective Partnerships with Individuals and Families. 4. Encourage and Support Individuals and Families to Engage More Fully in Their Health and with Their Health Care Team. 	
<p>Institute for Patient- and Family-Centered Care (IPFCC)</p> <p>Patient and Family Advisory Councils</p> <p>https://www.ipfcc.org/bestpractices/NYSHF_2018_PFAOnline_v3.pdf</p>	<p>Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals; Survey of NY hospitals.</p> <p>Recommendations:</p> <ol style="list-style-type: none"> 1. Build partnerships with patients and families into State and regional quality and safety initiatives. 2. Create opportunities for shared learning and mentorship around PFAC work. 3. Develop guidance to help hospitals access existing PFAC training resources in ways that address the need for tailored information. 4. Conduct additional research about the evolution and impact of PFACs and expand work to other states and settings. 5. Disseminate PFAC study results to share learnings within and outside of New York State. 	
<p>American Institutes for Research (AIR)</p> <p>Strategic Vision Roadmap for Person and Family Engagement (PFE)</p>	<p>Achieving the PFE Metrics to Improve Patient Safety and Health Equity.</p> <p>Six overarching strategies that are designed to help hospitals implement PFE practices—including the five PFE metrics—in ways that reflect and operationalize the core PFE principles.</p> <ol style="list-style-type: none"> 1. Organizational partnership 2. Patient and family preparation 3. Clinician and leadership preparation 4. Care, policy, and practice redesign 5. Measurement and research 6. Transparency and accountability 	

Strategy/Resources	Description of Strategy	Evidence/Implementation
<p>American Institutes for Research (AIR)</p> <p>Innovative Patient Engagement Strategies</p> <p>https://www.air.org/project/innovative-patient-engagement-strategies</p>	<p>AIR health experts conducted site visits to several accountable care organizations (ACOs - groups of doctors, hospitals, and other health care providers, who come together voluntarily to give coordinated high quality care to their Medicare patients) and primary care settings around the country to observe efforts by providers to increase patient involvement and engagement in their health care. Innovative patient engagement strategies observed included:</p> <ul style="list-style-type: none"> • Visiting patients in their homes allows providers to focus on providing efficient and effective care. One ACO achieved a 15 percent reduction in hospital admissions along with very high patient satisfaction scores. • Meeting end-stage renal disease patients at dialysis centers allows providers to support patients in following recommendations between appointments and coordinate care. This helped an ACO engage patients in ways that improved follow-up on important primary care needs. • Using a “nurse navigator” to follow up with patients over the phone helps providers understand patient needs, answer questions, and develop effective approaches. This increases patients’ understanding about their conditions and helped an ACO ensure it was providing proper at-home follow-up care. • Including patients and family caregivers in care teams and in developing and reviewing care plans to work through medical, social, psychological, and logistical issues helps providers better care for patients with multiple chronic issues, such as dementia or end-stage cancer. An ACO that developed integrated plans with patient and family input and engagement correlated this to more effective care and greater patient satisfaction. 	
<p>Agency for Healthcare Research and Quality (AHRQ)</p> <p>Engaging Patients and Families in Their Health Care</p> <p>https://www.ahrq.gov/patient-safety/resources/patient-family-engagement/index.html</p>	<p>The variety of resources offered by AHRQ in form of guides and tools for medical staff and patients and their caregiver to improve healthcare quality and safety in hospital and the primary care setting. Following are some examples of such guides and tools.</p>	

Strategy/Resources	Description of Strategy	Evidence/Implementation
<p>Agency for Healthcare Research and Quality (AHRQ)</p> <p>Guide to Patient and Family Engagement in Hospital Quality and Safety</p> <p>https://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/guide.html</p>	<p>The guide:</p> <ul style="list-style-type: none"> ○ Describes critical opportunities for hospitals to engage patients and families and to create partnerships between patients, families, and hospitals around the same goals. ○ Addresses real-world challenges. The Guide was developed, implemented, and evaluated with the input of patients, family members, clinicians, hospital staff, and hospital leaders. ○ Helps hospitals engage patients and families, which in turn can help improve quality and safety, respond to health care reform and accreditation standards, improve CAHPS® Hospital Survey scores, improve financial performance, and enhance market share and competitiveness. ○ Facilitates implementation and evaluation of each strategy with detailed guidance and customizable tools. <p>The Guide to Patient and Family Engagement in Hospital Quality and Safety is a tested, evidence-based resource to help hospitals work as partners with patients and families to improve quality and safety.</p>	
<p>Agency for Healthcare Research and Quality (AHRQ)</p> <p>Toolkit To Educate and Engage Residents and Family Members</p> <p>https://www.ahrq.gov/nhguide/toolkits/educate-and-engage/index.html</p>	<p>The Resident and Family Member Education toolkit helps the nursing home (1) encourage an open and respectful dialogue between nurses and prescribing clinicians and residents and their family members, and (2) help residents and family members participate in their care.</p>	
<p>Agency for Healthcare Research and Quality (AHRQ)</p> <p>Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families</p> <p>https://www.ahrq.gov/patientsafety/reports/engage.html</p>	<p>The Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families (the Guide) is a resource to help primary care practices partner with patients and their families to improve patient safety. The Guide is composed of materials and resources to help primary care practices implement patient and family engagement to improve patient safety.</p>	

Strategy/Resources	Description of Strategy	Evidence/Implementation
<p>Healthwise</p> <p>Patient Response: Giving Voice to the Patients (White paper)</p> <p>https://www.healthwise.org/resources/patient-responsevoicetopatient.aspx?back=%2fresources.aspx%3fsmartsearchfilter%3d4%3b</p>	<p>This white paper highlights the significance of patient responses and voices. Some quotes from paper:</p> <p>“While clinicians can now deliver good information to patients through their EMRs, there is no accepted use of IT standards that allows the patient’s voice to get back to the clinician.</p> <p>Patient response is a new way (and a new use of existing standards) to ensure that the patient’s voice can be well heard in creating care plans, in deciding among treatment options, and in advancing the doctor-patient partnership. By providing an easier way to pay more attention to the choices of our patients, we can finally put them at the center of care.</p> <p>In short, patient response provides the mechanism to routinely capture patients’ input in their electronic records so that physicians have easy access to the information.”</p>	
<p>Healthwise</p> <p>6 Keys to Keeping Your Diabetes Patients Engaged (Infographic information)</p> <p>https://www.healthwise.org/resources/keep-diabetes-patients-engaged.aspx?back=%2fresources.aspx</p>	<p>This infographic mentions the 6 key steps to engage diabetic patients in their care to improve clinical outcomes.</p> <ol style="list-style-type: none"> 1. Use technology to engage people 2. Touchbase frequently, both in and out of the clinic 3. Encourage people to treat themselves—the right way 4. Identify what’s in it for them 5. Create and celebrate milestones 6. Help patients focus on the future 	
<p>Healthwise</p> <p>Engaging Patients Within the Workflow Through Standards-Based Interoperability (eBrief)</p> <p>https://www.healthwise.org/resources/engaging-patientswithinworkflow.aspx?back=%2fresources.aspx%3fpage%3d4</p>	<p>This eBrief describes the ways of chronic care management services and engaging patients through EHR.</p> <p>“Using two reimbursement programs by Centers for Medicare and Medicaid Services (CMS), this eBrief will demonstrate how open APIs and standards-based interoperability offer a seamless medium for delivering health education and receiving important information back from the patient, such as a completed health risk assessment (HRA) or the patient’s preferences.”</p>	
<p>Healthwise</p> <p>8 Ways to Engage Your Hispanic Population (Infographic information)</p> <p>https://www.healthwise.org/resources/engage-your-hispanicpopulation.aspx?back=%2fresources.aspx%3fpage%3d4</p>	<ol style="list-style-type: none"> 1. Record member language preference in your system. 2. Increase physician awareness for coaching programs. 3. Implement a system that makes prescribing education easy. 4. Provide basic education first 5. Make sure key self-management materials are in English and Spanish. 6. Include easy to find Spanish education at your portal. 7. Reinforce self-management skills on an ongoing basis. 8. Track adherence to standards of care. 	

Strategy/Resources	Description of Strategy	Evidence/Implementation
Healthwise e-Coaching for Boomer Health (White paper) https://www.healthwise.org/resources/e-coaching-for-boomerhealth.aspx?back=%2fresources.aspx%3fsmartsearchfilter%3d4	This gray/white paper describes how Information Therapy (Ix®) Tools can give boomers the personalized and efficient health care experience they want and need. It highlights the need of disease specific personalized virtual/online coaching that help them in self-management and making better decisions for better health.	
Healthwise 8 Steps to Shared Decision Making Success for Care Management (Infographic information) https://www.healthwise.org/resources/shared-decision-makingsuccesscm.aspx?back=%2fresources.aspx%3fsmartsearchfilter%3d3%3b%26page%3d2	1. Engage clinicians and staff 2. Target individuals or populations for SDM 3. Identify and involve members for intervention 4. Distribute decision aids to members 5. Encourage decision aid viewing 6. Support SDM conversations 7. Measure the impact 8. Provide multilevel feedback	
Lucile Packard Foundation for Children's Health Five Top Tips for Engaging Families in Advisory Roles: Advice from a Family Leader https://www.lpfch.org/sites/default/files/field/publications/five_top_tips_12.19.18.pdf	A factsheet mentioning the advice and five tips from a family leader and PFAC chair for meaningfully engaging a group of family advisors. 1. Organization Values Families' Time and Input -compensation for family member in form of stipends, food etc 2. Organization Offers Ongoing Training and Support to Family Members 3. Organization Provides Support to Committee Chair 4. Chair Models Appropriate Facilitation and Behavior 5. Chair Builds Community, Cohesion, and Trust	
Lucile Packard Foundation for Children's Health A Framework for Assessing Family Engagement in Systems Change https://www.lpfch.org/sites/default/files/field/publications/assessing_family_engagement_4.10.18.pdf	This Issue Brief summarizes strategies for ensuring, enhancing, and supporting the meaningful engagement of families at the systems level of health care and the barriers to effective family engagement – findings from existing literature and a series of key informant interviews with family leaders and professionals. Further mentioned are four domains of family engagement in systems -Representation, Transparency, Impact and Commitment.	
Lucile Packard Foundation for Children's Health Engaging Families in Improving the Health Care System for Children with Special Health Care Needs https://www.lpfch.org/sites/default/files/field/publications/engaging_families_in_improving_the_health_care_system.pdf	This factsheet describes the findings from literature on evidence that patient and family engagement is essential and beneficial to get better patient outcomes. Further mentioned are the barriers to family engagement, strategies for improving organizations and health systems to engage family members effectively, and the role of Lucile Packard Foundation for Children's Health to support such activities to improve the process of family engagement for better health care system for children with special health care needs.	

Strategy/Resources	Description of Strategy	Evidence/Implementation
<p>Lucile Packard Foundation for Children's Health</p> <p>Creating and Sustaining Effective Hospital Family Advisory Councils: Findings from the California Patient and Family Centered Care Network of Pediatric Hospitals</p> <p>https://www.lpfch.org/sites/default/files/field/publications/creating_and_sustaining_effective_hospital_family_advisory_councils.pdf</p>	<p>To support the development of effective FACs in pediatric settings, the Lucile Packard Foundation for Children's Health provided grant funding in 2012 to create the California Patient & Family Centered Care Network (CA-PFCC). The primary goal of the Network is to share ideas and resources to facilitate the formation of sustainable Family Advisory Councils in health care settings. To achieve this goal, Network members participated in a range of activities (webinars, ideation sessions, and work groups) to gather information about the current state of FACs in California. This report shares the results of analyzed data that helped in identification of foundational elements of FACs: function, venue, authority, and membership configuration. Collectively, this work resulted in a checklist of key activities intended to guide the creation of new FACs and to enhance and expand the work of existing Councils.</p>	
<p>Lucile Packard Foundation for Children's Health</p> <p>A Guide to Establishing Effective Hospital Family Advisory Councils</p> <p>https://www.lpfch.org/sites/default/files/field/publications/a_guide_to_establishing_effective_hospital_family_advisory_councils_0.pdf</p>	<p>This fact sheet describes the shared experiences of network members of California Patient & Family Centered Care Network with FACs and a checklist for establishing effective Councils.</p>	
<p>Children's Hospital Association</p> <p>Invoking the Power of Family Partnerships to Improve Outcomes for Children with Medical Complexity</p> <p>https://www.childrenshospitals.org/-/media/Files/CHA/Main/Programs_and_Services/Quality_Safety_and_Performance/CARE/care_081318_invoking_power_family_partnerships.pdf?la=en&hash=C0B173FA84AEF23E63A4744575376BDAE447293D</p>	<p>This paper mentions briefly the 10 vital actions for effective family partnerships and levels of family involvement. It also reports the CARE Award Model (The Coordinating All Resources Effectively) designed to transform care through the provision of appropriate, coordinated care in the right setting, and develop alternative payment models that more effectively align with the new care model. The CARE Award called for the direct participation of families on quality improvement (QI) teams, and in the design and evaluation of clinical methods and tools grounded in shared decision-making with families and members of their health care team. Highlighted are findings of different QI projects by member organizations.</p>	

Strategy/Resources	Description of Strategy	Evidence/Implementation
Family Voices Family Engagement in Systems: A Literature Review http://familyvoices.org/wp-content/uploads/2018/10/Engagement-Assessment-literature-4.10.18_r4.26.18.pdf	This literature review used various peer-reviewed articles and grey literature resources to describe wide ranging and sophisticated approaches to patient and family engagement being practiced today, and provide a picture of a vibrant and increasingly evidence-based field of study. According to author, “the Family Voices project, Framework for Assessing Family Engagement, addresses the topic of ensuring and enhancing the role and participation of families in all aspects of the systems on which CYSHCN depend. The purpose of the work was to develop a brief that 1) establishes key characteristics of effective family engagement in systems level programs and 2) outlines specific actions to build an assessment based on those key criteria.”	
Family Voices Family Voices	Family Voices is a national family-led organization of families and friends of children and youth with special health care needs (CYSHCN) and disabilities. Multiple resources related to patient and family engagement including white papers and reports listed at Family Voices site. https://familyvoices.org/resources/	
American Cancer Society Caregiver Resource Guide https://www.cancer.org/treatment/caregivers/caregiver-resource-guide.html#_	“The American Cancer Society Caregiver Resource Guide is a tool for people who are caring for someone with cancer. It can help you: learn how to care for yourself as a caregiver, better understand what your loved one is going through, develop skills for coping and caring, and take steps to help protect your health and well-being.”	
American Cancer Society The Doctor-Patient Relationship https://www.cancer.org/treatment/finding-and-paying-for-treatment/choosing-your-treatment-team/the-doctor-patient-relationship.html	Information and guide on patient activation. What cancer patients should expect and ask from physicians to make informed decisions for their health.	
American Heart Association Caregiver Support https://www.heart.org/en/health-topics/caregiver-support	Multiple resources addressing the needs of caregivers and tips for them to stay healthy and provide better care to their loved ones with various cardiac diseases. Resources and educational material for specific disease also available.	

Strategy/Resources	Description of Strategy	Evidence/Implementation
Institute for Clinical Systems Improvement (ICSI) Going Beyond Clinical Walls https://www.icsi.org/going-beyond-clinical-walls/ https://www.nrhi.org/nrhi-member-work/patient-and-community-engagement/	Resources and guide designed ICSI to support conversations that identify problems and opportunities, develop a shared vision for connections with community partners, and build practical next steps. Engaging health care audiences to examine the benefits and possibilities of connecting with the community for solving complex problems, Identifying examples of current and potentially-available community resources, and Sharing knowledge, using data and exploring mutual goals as a way to build common ground with community partners.	
Community Catalyst Center for Consumer Engagement in Health Innovation https://www.healthinnovation.org/ https://www.communitycatalyst.org/initiatives-and-issues/initiatives/center-for-consumer-engagement-in-health-innovation/full-description https://www.healthinnovation.org/resources/toolkits/meaningful-consumer-engagement	“The Center provides resources and expertise to ensure that patients and families, particularly the most vulnerable, have a voice at all levels of the health care delivery system — from individual care to health system design to state and national policy.”	
Patient Engagement Hit Patient Engagement Strategies https://patientengagementhit.com/tag/patient-engagement-strategies	Plenty of resources and guides for patient and family engagement, shared decision making and chronic disease management; highlighting the vulnerable population.	

Appendix D. List of Excluded Studies for Systematic Reviews

Studies are sorted by the reason for exclusion.

Does not apply to the Key Question

1. Lombardero A, Hansen CD, Richie AE, et al. A Narrative Review of the Literature on Insufficient Sleep, Insomnia, and Health Correlates in American Indian/Alaska Native Populations. *Journal of environmental and public health*. 2019;2019:4306463. PMID: 31360174.
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7. McGilton KS, Vellani S, Yeung L, et al. Identifying and understanding the health and social care needs of older adults with multiple chronic conditions and their caregivers: a scoping review. *BMC geriatrics*. 2018 Oct 1;18(1):231. PMID: 30285641.
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12. Ghazisaeidi M, Safdari R, Goodini A, et al. Digital games as an effective approach for cancer management: Opportunities and challenges. *Journal of education and health promotion*. 2017;6:30. PMID: 28584830.
13. Hanlon P, Daines L, Campbell C, et al. Telehealth Interventions to Support Self-Management of Long-Term Conditions: A Systematic Metareview of Diabetes, Heart Failure, Asthma, Chronic Obstructive Pulmonary Disease, and Cancer. *Journal of medical Internet research*. 2017 May 17;19(5):e172. PMID: 28526671.
14. Wilson MG, Lavis JN, Gauvin FP. Designing Integrated Approaches to Support People with Multimorbidity: Key Messages from Systematic Reviews, Health System Leaders and Citizens. *Healthcare policy = Politiques de sante*. 2016 Nov;12(2):91-104. PMID: 28032827.
15. Kessler D, Liddy C. An integrative literature review to examine the provision of self-management support following transient ischaemic attack. *Journal of clinical nursing*. 2017 Nov;26(21-22):3256-70. PMID: 28001339.
16. Brzan PP, Rotman E, Pajnikihar M, et al. Mobile Applications for Control and Self Management of Diabetes: A Systematic Review. *Journal of medical systems*. 2016 Sep;40(9):210. PMID: 27520615.
17. Kitsiou S, Pare G, Jaana M. Effects of home telemonitoring interventions on patients with chronic heart failure: an overview of systematic reviews. *Journal of medical Internet research*. 2015 Mar 12;17(3):e63. PMID: 25768664.

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20. Finset A. Special Section: Review articles on decision making and patient education interventions. *Patient education and counseling*. 2017 Dec;100(12):2157-8. PMID: 29032951.
21. Doody O, Butler MP, Lyons R, et al. Families' experiences of involvement in care planning in mental health services: an integrative literature review. *Journal of psychiatric and mental health nursing*. 2017 Aug;24(6):412-30. PMID: 28102020.
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23. Scholz B, Gordon S, Happell B. Consumers in mental health service leadership: A systematic review. *International journal of mental health nursing*. 2017 Feb;26(1):20-31. PMID: 28093883.
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Others

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2. Mollard E, Michaud K. Mobile Apps for Rheumatoid Arthritis: Opportunities and Challenges. *Rheumatic diseases clinics of North America*. 2019 May;45(2):197-209. PMID: 30952393.
3. Sample D, Turner J. Improving gluten free diet adherence by youth with celiac disease. *International journal of adolescent medicine and health*. 2019 Mar 15. PMID: 30875325.
4. Maddison R, Cartledge S, Rogerson M, et al. Usefulness of Wearable Cameras as a Tool to Enhance Chronic Disease Self-Management: Scoping Review. *JMIR mHealth and uHealth*. 2019 Jan 3;7(1):e10371. PMID: 30609985.
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7. Byambasuren O, Sanders S, Beller E, et al. Prescribable mHealth apps identified from an overview of systematic reviews. *NPJ digital medicine*. 2018;1:12. PMID: 31304297.

8. Marcolino MS, Oliveira JAQ, D'Agostino M, et al. The Impact of mHealth Interventions: Systematic Review of Systematic Reviews. *JMIR mHealth and uHealth*. 2018 Jan 17;6(1):e23. PMID: 29343463.
9. Lamore K, Montalescot L, Untas A. Treatment decision-making in chronic diseases: What are the family members' roles, needs and attitudes? A systematic review. *Patient education and counseling*. 2017 Dec;100(12):2172-81. PMID: 28838630.
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12. Wilson MG, Lavis JN, Gauvin FP. Designing Integrated Approaches to Support People with Multimorbidity: Key Messages from Systematic Reviews, Health System Leaders and Citizens. *Healthcare policy = Politiques de sante*. 2016 Nov;12(2):91-104. PMID: 28032827.
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15. Matthew-Maich N, Harris L, Ploeg J, et al. Designing, Implementing, and Evaluating Mobile Health Technologies for Managing Chronic Conditions in Older Adults: A Scoping Review. *JMIR mHealth and uHealth*. 2016 Jun 9;4(2):e29. PMID: 27282195.
16. Ganguli A, Clewell J, Shillington AC. The impact of patient support programs on adherence, clinical, humanistic, and economic patient outcomes: a targeted systematic review. *Patient preference and adherence*. 2016;10:711-25. PMID: 27175071.
17. Flodgren G, Rachas A, Farmer AJ, et al. Interactive telemedicine: effects on professional practice and health care outcomes. *The Cochrane database of systematic reviews*. 2015 Sep 7(9):Cd002098. PMID: 26343551.
18. Button K, Roos PE, Spasic I, et al. The clinical effectiveness of self-care interventions with an exercise component to manage knee conditions: A systematic review. *The Knee*. 2015 Oct;22(5):360-71. PMID: 26056046.
19. Dukhanin V, Topazian R, DeCamp M. Metrics and Evaluation Tools for Patient Engagement in Healthcare Organization- and System-Level Decision-Making: A Systematic Review. *International journal of health policy and management*. 2018 Oct 1;7(10):889-903. PMID: 30316241.
20. Finset A. Special Section: Review articles on decision making and patient education interventions. *Patient education and counseling*. 2017 Dec;100(12):2157-8. PMID: 29032951.
21. Olding M, McMillan SE, Reeves S, et al. Patient and family involvement in adult critical and intensive care settings: a scoping review. *Health expectations : an international journal of*

public participation in health care and health policy. 2016 Dec;19(6):1183-202. PMID: 27878937.

22. Oczkowski SJ, Chung HO, Hanvey L, et al. Communication tools for end-of-life decision-making in the intensive care unit: a systematic review and meta-analysis. *Critical care* (London, England). 2016 Apr 9;20:97. PMID: 27059989.

23. Kynoch K, Chang A, Coyer F, et al. The effectiveness of interventions to meet family needs of critically ill patients in an adult intensive care unit: a systematic review update. *JBIC database of systematic reviews and implementation reports*. 2016 Mar;14(3):181-234. PMID: 27532144.

24. Gagliardi AR, Legare F, Brouwers MC, et al. Patient-mediated knowledge translation (PKT) interventions for clinical encounters: a systematic review. *Implementation science : IS*. 2016 Feb 29;11:26. PMID: 26923462.

25. Snyder H, Engstrom J. The antecedents, forms and consequences of patient involvement: A narrative review of the literature. *International journal of nursing studies*. 2016 Jan;53:351-78. PMID: 26602069.

Does not report any of the outcomes of interest (QoL, Patient satisfaction/experience, Medication adherence, Healthcare utilization, Chronic disease management outcome, Implementation measure)

1. Tricco AC, Ashoor HM, Cardoso R, et al. Sustainability of knowledge translation interventions in healthcare decision-making: a scoping review. *Implementation science : IS*. 2016 Apr 21;11:55. PMID: 27097827.

2. Kogan AC, Wilber K, Mosqueda L. Person-Centered Care for Older Adults with Chronic Conditions and Functional Impairment: A Systematic Literature Review. *Journal of the American Geriatrics Society*. 2016 Jan;64(1):e1-7. PMID: 26626408.

3. Vromans RD, van Eenbergen MC, Pauws SC, et al. Communicative aspects of decision aids for localized prostate cancer treatment - A systematic review. *Urologic oncology*. 2019 Jul;37(7):409-29. PMID: 31053529.

4. Dogba MJ, Dossa AR, Breton E, et al. Using information and communication technologies to involve patients and the public in health education in rural and remote areas: a scoping review. *BMC health services research*. 2019 Feb 19;19(1):128. PMID: 30782147.

5. Simblett S, Greer B, Matcham F, et al. Barriers to and Facilitators of Engagement With Remote Measurement Technology for Managing Health: Systematic Review and Content Analysis of Findings. *Journal of medical Internet research*. 2018 Jul 12;20(7):e10480. PMID: 30001997.

6. Menichetti J, Graffigna G, Steinsbekk A. What are the contents of patient engagement interventions for older adults? A systematic review of randomized controlled trials. *Patient education and counseling*. 2018 Jun;101(6):995-1005. PMID: 29246493.

7. Young A, Menon D, Street J, et al. Exploring patient and family involvement in the lifecycle of an orphan drug: a scoping review. *Orphanet journal of rare diseases*. 2017 Dec 22;12(1):188. PMID: 29273068.

8. Schmidt K, Damm K, Prenzler A, et al. Preferences of lung cancer patients for treatment and decision-making: a systematic literature review. *European journal of cancer care*. 2016 Jul;25(4):580-91. PMID: 26676876.
9. Walsh S, Golden E, Priebe S. Systematic review of patients' participation in and experiences of technology-based monitoring of mental health symptoms in the community. *BMJ open*. 2016 Jun 21;6(6):e008362. PMID: 27329437.
10. Menon D, Stafinski T, Dunn A, et al. Involving patients in reducing decision uncertainties around orphan and ultra-orphan drugs: a rare opportunity? *The patient*. 2015 Feb;8(1):29-39. PMID: 25516506.
11. Waid J, Kelly M. Supporting family engagement with child and adolescent mental health services: A scoping review. *Health Soc Care Community*. 2020 Jan 17. doi: 10.1111/hsc.12947. Epub ahead of print. PMID: 31951087.
12. Menear M, Dugas M, Careau E, Chouinard MC, Dogba MJ, Gagnon MP, Gervais M, Gilbert M, Houle J, Kates N, Knowles S, Martin N, Nease DE Jr, Zomahoun HTV, Légaré F. Strategies for engaging patients and families in collaborative care programs for depression and anxiety disorders: A systematic review. *J Affect Disord*. 2020 Feb 15;263:528-539. doi: 10.1016/j.jad.2019.11.008. Epub 2019 Nov 4. PMID: 31744737.

Appendix E. List of Excluded Studies for Original Articles

Studies are sorted by the reason for exclusion.

Does not apply to the Key Question

1. Gordon WJ, Bates DW, Fuchs D, et al. Comparing Characteristics of Patients Who Connect Their iPhones to an Electronic Health Records System Versus Patients Who Connect Without Personal Devices: Cohort Study. *Journal of medical Internet research*. 2019 Aug 22;21(8):e14871. PMID: 31441430.
2. Carmel AS, Cornelius-Schechter A, Frankel B, et al. Evaluation of the Patient Activated Learning System (PALS) to improve knowledge acquisition, retention, and medication decision making among hypertensive adults: Results of a pilot randomized controlled trial. *Patient education and counseling*. 2019 Aug;102(8):1467-74. PMID: 30928344.
3. Bajracharya AS, Crotty BH, Kowoloff HB, et al. Patient experience with family history tool: analysis of patients' experience sharing their family health history through patient-computer dialogue in a patient portal. *Journal of the American Medical Informatics Association : JAMIA*. 2019 Jul 1;26(7):603-9. PMID: 30946464.
4. Minneci PC, Cooper JN, Leonhart K, et al. Effects of a Patient Activation Tool on Decision Making Between Surgery and Nonoperative Management for Pediatric Appendicitis: A Randomized Clinical Trial. *JAMA network open*. 2019 Jun 5;2(6):e195009. PMID: 31173118.
5. Brice YN, Joynt KE, Tompkins CP, et al. Meaningful Use and Hospital Performance on Post-Acute Utilization Indicators. *Health services research*. 2018 Apr;53(2):803-23. PMID: 28255995.
6. Jiang S, Hong YA. Mobile-based patient-provider communication in cancer survivors: The roles of health literacy and patient activation. *Psycho-oncology*. 2018 Mar;27(3):886-91. PMID: 29193503.
7. Gibson B, Butler J, Doyon K, et al. Veterans Like Me: Formative evaluation of a patient decision aid design. *Journal of biomedical informatics*. 2017 Jul;71s:S46-s52. PMID: 27623534.
8. Aslakson RA, Isenberg SR, Crossnohere NL, et al. Utilising advance care planning videos to empower perioperative cancer patients and families: a study protocol of a randomised controlled trial. *BMJ open*. 2017 Jun 6;7(5):e016257. PMID: 28592584.
9. Taylor LJ, Rathouz PJ, Berlin A, et al. Navigating high-risk surgery: protocol for a multisite, stepped wedge, cluster-randomised trial of a question prompt list intervention to empower older adults to ask questions that inform treatment decisions. *BMJ open*. 2017 May 29;7(5):e014002. PMID: 28554911.
10. Lawrence D, Miller JH, C WF. Medication Adherence. *Journal of clinical pharmacology*. 2017 Apr;57(4):422-7. PMID: 28105688.

11. An J. The Impact of Patient-Centered Medical Homes on Quality of Care and Medication Adherence in Patients with Diabetes Mellitus. *Journal of managed care & specialty pharmacy*. 2016 Nov;22(11):1272-84. PMID: 27783547.
12. Simmons K, Gibson S, White JM. Drivers Advancing Oral Health in a Large Group Dental Practice Organization. *The journal of evidence-based dental practice*. 2016 Jun;16 Suppl:104-12. PMID: 27237003.
13. Tothy AS, Limper HM, Driscoll J, et al. The Ask Me to Explain Campaign: A 90-Day Intervention to Promote Patient and Family Involvement in Care in a Pediatric Emergency Department. *Joint Commission journal on quality and patient safety*. 2016 Jun;42(6):281-5. PMID: 27184244.
14. Purkable BA, Mold JW, Chen S. Encouraging Patient-Centered Care by Including Quality-of-Life Questions on Pre-Encounter Forms. *Annals of family medicine*. 2016 May;14(3):221-6. PMID: 27184992.
15. Altshuler L, Plaksin J, Zabar S, et al. Transforming the Patient Role to Achieve Better Outcomes Through a Patient Empowerment Program: A Randomized Wait-List Control Trial Protocol. *JMIR research protocols*. 2016 Apr 21;5(2):e68. PMID: 27103306.
16. Serpico V, Liepert AE, Boucher K, et al. The Effect of Previsit Education in Breast Cancer Patients: A Study of a Shared-decision-making Tool. *The American surgeon*. 2016 Mar;82(3):259-65. PMID: 27099063.
17. Hayes RM, Wickline A, Hensley C, et al. A Quality Improvement Project to Improve Family Recognition of Medical Team Member Roles. *Hospital pediatrics*. 2015 Sep;5(9):480-6. PMID: 26330247.
18. Spertus JA, Bach R, Bethea C, et al. Improving the process of informed consent for percutaneous coronary intervention: patient outcomes from the Patient Risk Information Services Manager (ePRISM) study. *American heart journal*. 2015 Feb;169(2):234-41.e1. PMID: 25641532.
19. Tassone C, Keshavjee K, Paglialonga A, Moreira N, Pinto J, Quintana Y. Evaluation of mobile apps for treatment of patients at risk of developing gestational diabetes. *Health Informatics J*. 2020 Jan 8;1460458219896639. doi: 10.1177/1460458219896639. Epub ahead of print. PMID: 31912754.

No comparison group

1. Quinn CC, Staub S, Barr E, et al. Mobile Support for Older Adults and Their Caregivers: Dyad Usability Study. *JMIR aging*. 2019 May 23;2(1):e12276. PMID: 31518271.
2. Kata A, Sudore R, Finlayson E, et al. Increasing Advance Care Planning Using a Surgical Optimization Program for Older Adults. *Journal of the American Geriatrics Society*. 2018 Oct;66(10):2017-21. PMID: 30289968.

3. Selter A, Tsangouri C, Ali SB, et al. An mHealth App for Self-Management of Chronic Lower Back Pain (Limbr): Pilot Study. *JMIR mHealth and uHealth*. 2018 Sep 17;6(9):e179. PMID: 30224333.
4. Jiang S, Hong YA. Mobile-based patient-provider communication in cancer survivors: The roles of health literacy and patient activation. *Psycho-oncology*. 2018 Mar;27(3):886-91. PMID: 29193503.
5. Woolf SH, Krist AH, Lafata JE, et al. Engaging Patients in Decisions About Cancer Screening: Exploring the Decision Journey Through the Use of a Patient Portal. *American journal of preventive medicine*. 2018 Feb;54(2):237-47. PMID: 29241715.
6. Forcino RC, Barr PJ, O'Malley AJ, et al. Using CollaboRATE, a brief patient-reported measure of shared decision making: Results from three clinical settings in the United States. *Health expectations : an international journal of public participation in health care and health policy*. 2018 Feb;21(1):82-9. PMID: 28678426.
7. Hines AL, Roter D, Ghods Dinoso BK, et al. Informed and patient-centered decision-making in the primary care visits of African Americans with depression. *Patient education and counseling*. 2018 Feb;101(2):233-40. PMID: 28779910.
8. Byrne C, Kurmas N, Burant CJ, et al. Cooking Classes: A Diabetes Self-Management Support Intervention Enhancing Clinical Values. *The Diabetes educator*. 2017 Dec;43(6):600-7. PMID: 29047323.
9. Whitney E, Kindred E, Pratt A, et al. Culturally Tailoring a Patient Empowerment and Diabetes Education Curriculum for the African American Church. *The Diabetes educator*. 2017 Oct;43(5):441-8. PMID: 28793835.
10. Gibson B, Butler J, Doyon K, et al. Veterans Like Me: Formative evaluation of a patient decision aid design. *Journal of biomedical informatics*. 2017 Jul;71s:S46-s52. PMID: 27623534.
11. Marshall AP, Lemieux M, Dhaliwal R, et al. Novel, Family-Centered Intervention to Improve Nutrition in Patients Recovering From Critical Illness: A Feasibility Study. *Nutrition in clinical practice : official publication of the American Society for Parenteral and Enteral Nutrition*. 2017 Jun;32(3):392-9. PMID: 28537514.
12. de Jong M, van der Meulen-de Jong A, Romberg-Camps M, et al. Development and Feasibility Study of a Telemedicine Tool for All Patients with IBD: MyIBDcoach. *Inflammatory bowel diseases*. 2017 Apr;23(4):485-93. PMID: 28267047.
13. Tothy AS, Limper HM, Driscoll J, et al. The Ask Me to Explain Campaign: A 90-Day Intervention to Promote Patient and Family Involvement in Care in a Pediatric Emergency Department. *Joint Commission journal on quality and patient safety*. 2016 Jun;42(6):281-5. PMID: 27184244.

14. Gibson A, Cooper M, Rae J, Hayes J. Clients' experiences of shared decision making in an integrative psychotherapy for depression. *J Eval Clin Pract*. 2019 Dec 1. doi: 10.1111/jep.13320. Epub ahead of print. PMID: 31788932.

Not in English

1. Pons Rafols JM, Moharra Frances M. [Shared decision making]. *Medicina clinica*. 2016 Mar 4;146(5):205-6. PMID: 26589733.

2. Gröger S, Mäder-Porombka C, Stang C, Wallacher S. Partizipative Entscheidungsfindung bei Prostatakrebspatienten [Shared decision-making in prostate cancer patients]. *Urologe A*. 2019 Nov;58(11):1324-1330. German. doi: 10.1007/s00120-018-0774-4. PMID: 30238132.

Non-USA based study

1. Vankan E, Schoorel E, van Kuijk S, et al. The effect of the use of a decision aid with individual risk estimation on the mode of delivery after a caesarean section: A prospective cohort study. *PloS one*. 2019;14(9):e0222499. PMID: 31557177.

2. Clarke AL, Roscoe J, Appleton R, et al. Promoting integrated care in prostate cancer through online prostate cancer-specific holistic needs assessment: a feasibility study in primary care. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*. 2019 Jul 23. PMID: 31338642.

3. Guo Y, Lane DA, Wang L, et al. Mobile Health (mHealth) technology for improved screening, patient involvement and optimising integrated care in atrial fibrillation: The mAFA (mAF-App) II randomised trial. *International journal of clinical practice*. 2019 Jul;73(7):e13352. PMID: 31002434.

4. Burns K, McBride CA, Patel B, et al. Creating Consumer-Generated Health Data: Interviews and a Pilot Trial Exploring How and Why Patients Engage. *Journal of medical Internet research*. 2019 Jun 13;21(6):e12367. PMID: 31199312.

5. Mata J, Pecorelli N, Kaneva P, et al. A mobile device application (app) to improve adherence to an enhanced recovery program for colorectal surgery: a randomized controlled trial. *Surgical endoscopy*. 2019 May 13. PMID: 31087175.

6. Chao DY, Lin TM, Ma WY. Enhanced Self-Efficacy and Behavioral Changes Among Patients With Diabetes: Cloud-Based Mobile Health Platform and Mobile App Service. *JMIR diabetes*. 2019 May 10;4(2):e11017. PMID: 31094324.

7. Zuidema R, van Dulmen S, Nijhuis-van der Sanden M, et al. Efficacy of a Web-Based Self-Management Enhancing Program for Patients with Rheumatoid Arthritis: Explorative Randomized Controlled Trial. *Journal of medical Internet research*. 2019 Apr 30;21(4):e12463. PMID: 31038461.

8. Reumkens K, de Die-Smulders CEM, van Osch L. Exploring the preferences of involved health professionals regarding the implementation of an online decision aid to support couples

during reproductive decision-making in hereditary cancer: a mixed methods approach. *Familial cancer*. 2019 Apr;18(2):285-91. PMID: 30656480.

9. Luhr K, Eldh AC, Theander K, et al. Effects of a self-management programme on patient participation in patients with chronic heart failure or chronic obstructive pulmonary disease: A randomized controlled trial. *European journal of cardiovascular nursing : journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology*. 2019 Mar;18(3):185-93. PMID: 30277807.

10. McCusker J, Lambert SD, Haggerty J, et al. Self-management support in primary care is associated with improvement in patient activation. *Patient education and counseling*. 2019 Mar;102(3):571-7. PMID: 30497799.

11. Henselmans I, van Laarhoven HWM, de Haes H, et al. Training for Medical Oncologists on Shared Decision-Making About Palliative Chemotherapy: A Randomized Controlled Trial. *The oncologist*. 2019 Feb;24(2):259-65. PMID: 29959285.

12. Withidpanyawong U, Lerkiatbundit S, Saengcharoen W. Family-based intervention by pharmacists for type 2 diabetes: A randomised controlled trial. *Patient education and counseling*. 2019 Jan;102(1):85-92. PMID: 30150128.

13. Nost TH, Steinsbekk A, Bratas O, et al. Twelve-month effect of chronic pain self-management intervention delivered in an easily accessible primary healthcare service - a randomised controlled trial. *BMC health services research*. 2018 Dec 29;18(1):1012. PMID: 30594190.

14. Bonin K, McGuffin M, Lechtman E, et al. Evaluation of an Online Education Resource on Radiation Therapy Created for Patients with Postprostatectomy Prostate Cancer and Their Caregivers. *Journal of medical imaging and radiation sciences*. 2018 Dec;49(4):365-70. PMID: 30514552.

15. Davins Riu M, Borrás Pérez X, Artigas Raventos V, et al. Use of Telehealth as a New Model for Following Intermittent Claudication and Promoting Patient Expertise. *Telemedicine journal and e-health : the official journal of the American Telemedicine Association*. 2018 Oct;24(10):773-81. PMID: 29323628.

16. Kapell Brown C, Kryworuchko J, Martin W. Evaluation of the CPR video decision aid with patients with end stage renal disease. *BMC nephrology*. 2018 Sep 12;19(1):226. PMID: 30208850.

17. Risling T, Martinez J, Young J, et al. Defining Empowerment and Supporting Engagement Using Patient Views From the Citizen Health Information Portal: Qualitative Study. *JMIR medical informatics*. 2018 Sep 10;6(3):e43. PMID: 30201603.

18. Amundsen A, Bergvik S, Butow P, et al. Supporting doctor-patient communication: Providing a question prompt list and audio recording of the consultation as communication aids to outpatients in a cancer clinic. *Patient education and counseling*. 2018 Sep;101(9):1594-600. PMID: 29703493.

19. Au SS, Roze des Ordon AL, Parsons Leigh J, et al. A Multicenter Observational Study of Family Participation in ICU Rounds. *Critical care medicine*. 2018 Aug;46(8):1255-62. PMID: 29742590.
20. Tinsel I, Siegel A, Schmoor C, et al. Encouraging Self-Management in Cardiovascular Disease Prevention. *Deutsches Arzteblatt international*. 2018 Jul 9;115(27-28):469-76. PMID: 30064627.
21. Baijens SWE, Huppelschoten AG, Van Dillen J, et al. Improving shared decision-making in a clinical obstetric ward by using the three questions intervention, a pilot study. *BMC pregnancy and childbirth*. 2018 Jul 4;18(1):283. PMID: 29973187.
22. Melissant HC, Verdonck-de Leeuw IM, Lissenberg-Witte BI, et al. 'Oncokompas', a web-based self-management application to support patient activation and optimal supportive care: a feasibility study among breast cancer survivors. *Acta oncologica (Stockholm, Sweden)*. 2018 Jul;57(7):924-34. PMID: 29451059.
23. Jegan NRA, Kurwitz SA, Kramer LK, et al. The effect of a new lifetime-cardiovascular-risk display on patients' motivation to participate in shared decision-making. *BMC family practice*. 2018 Jun 9;19(1):84. PMID: 29885661.
24. Li LC, Shaw CD, Lacaille D, et al. Effects of a Web-Based Patient Decision Aid on Biologic and Small-Molecule Agents for Rheumatoid Arthritis: Results From a Proof-of-Concept Study. *Arthritis care & research*. 2018 Mar;70(3):343-52. PMID: 28544648.
25. Nafradi L, Nakamoto K, Csabai M, et al. An empirical test of the Health Empowerment Model: Does patient empowerment moderate the effect of health literacy on health status? *Patient education and counseling*. 2018 Mar;101(3):511-7. PMID: 28899712.
26. Ruiz-Baques A, Contreras-Porta J, Marques-Mejias M, et al. Evaluation of an Online Educational Program for Parents and Caregivers of Children With Food Allergies. *Journal of investigational allergology & clinical immunology*. 2018;28(1):37-41. PMID: 29461207.
27. Dinius J, Gaupp R, Becker S, et al. Patient Safety in Hospitals: What We Do and What We Need-Focus Groups With Stakeholders of Hospitals in Southern Germany. *Journal of patient safety*. 2017 Dec 15. PMID: 29252966.
28. Ryu B, Kim N, Heo E, et al. Impact of an Electronic Health Record-Integrated Personal Health Record on Patient Participation in Health Care: Development and Randomized Controlled Trial of MyHealthKeeper. *Journal of medical Internet research*. 2017 Dec 7;19(12):e401. PMID: 29217503.
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Not an original article

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Does not report any of the outcomes of interest (QoL, Patient satisfaction/experience, Medication adherence, Healthcare utilization, Chronic disease management outcome, Implementation measure)

1. Moore BA, Buono FD, Printz DMB, et al. Customized recommendations and reminder text messages for automated, computer-based treatment during methadone. *Experimental and clinical psychopharmacology*. 2017 Dec;25(6):485-95. PMID: 29251978.
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Other

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Appendix F. List of Included Studies for Original Articles

Original articles search – List of articles included for direct patient care strategy

1. Subramanian L, Zhao J, Zee J, et al. Use of a Decision Aid for Patients Considering Peritoneal Dialysis and In-Center Hemodialysis: A Randomized Controlled Trial. *American journal of kidney diseases : the official journal of the National Kidney Foundation*. 2019 Sep;74(3):351-60. doi: 10.1053/j.ajkd.2019.01.030. PMID: 30954312.
2. Carroll JK, Tobin JN, Luque A, et al. "Get Ready and Empowered About Treatment" (GREAT) Study: a Pragmatic Randomized Controlled Trial of Activation in Persons Living with HIV. *Journal of general internal medicine*. 2019 Sep;34(9):1782-9. doi: 10.1007/s11606-019-05102-7. PMID: 31240605.
3. Kamal AH, Wolf S, Nicolla JM, et al. Usability of PCforMe in Patients With Advanced Cancer Referred to Outpatient Palliative Care: Results of a Randomized, Active-Controlled Pilot Trial. *Journal of pain and symptom management*. 2019 Sep;58(3):382-9. doi: 10.1016/j.jpainsymman.2019.05.007. PMID: 31163259.
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8. Biederman J, Fried R, DiSalvo M, et al. A Novel Text Message Intervention to Improve Adherence to Stimulants in Adults With Attention Deficit/Hyperactivity Disorder. *Journal of clinical psychopharmacology*. 2019 Jul/Aug;39(4):351-6. doi: 10.1097/jcp.0000000000001055. PMID: 31162154.
9. Potter JE, Duthely LM, Diaz-Mendez N, et al. Implementing CenteringPregnancy Group Prenatal Care for Minority Women Living with HIV at an Urban University Hospital. *Journal of midwifery & women's health*. 2019 Jul;64(4):451-61. doi: 10.1111/jmwh.12987. PMID: 31222899.
10. Struwe LA, Schmaderer MS, Zimmerman L. Changes in Patient Activation in a Self-Management Intervention. *Western journal of nursing research*. 2019 May 16;193945919848091. doi: 10.1177/0193945919848091. PMID: 31092139.

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12. Gassaway J, Jones ML, Sweatman WM, et al. Peer-led, transformative learning approaches increase classroom engagement in care self-management classes during inpatient rehabilitation of individuals with spinal cord injury. *The journal of spinal cord medicine*. 2019 May;42(3):338-46. doi: 10.1080/10790268.2017.1385992. PMID: 29037112.
13. Lauffenburger JC, Ghazinouri R, Jan S, et al. Impact of a novel pharmacist-delivered behavioral intervention for patients with poorly-controlled diabetes: The ENhancing outcomes through Goal Assessment and Generating Engagement in Diabetes Mellitus (ENGAGE-DM) pragmatic randomized trial. *PloS one*. 2019;14(4):e0214754. doi: 10.1371/journal.pone.0214754. PMID: 30939143.
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20. Moore BA, Buono FD, Lloyd DP, et al. A randomized clinical trial of the Recovery Line among methadone treatment patients with ongoing illicit drug use. *Journal of substance abuse treatment*. 2019 Feb;97:68-74. doi: 10.1016/j.jsat.2018.11.011. PMID: 30577901.
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Appendix G. Word Cloud

The strategies, barriers, and facilitators related to patient and family engagement suggested by our Key Informants using Poll Everywhere.

- Status Quo Bias- Hard To Start Something New - Resistance To Change/Too Much Work To Add Another Thing
- Need To Streamline For Families When Need To Engage For Multiple Family Members
- No Requirement For Clinics And Hospitals To Engage Patients And Families
- Patient Confidence In Decision Making (E.G., Using A Tool Such As Sure)
- Medical Culture That Does Not Prioritize/Value Patient And Family Input
- Patient Use Of Portal, Apps, Other Electronic Engagement Tools
- Difficulty Selecting To Right Tools And Standardizing Protocols
- Look Upstream To See How Well You Capture The Population
- Portal Helps Input And Share Data With Multiple Providers
- Lack Of Trust/Evidence That It Will Be Helpful/Useful
- Structure Of Care System Doesn't Accommodate PFE
- Lack Of Payer And Health System Support
- Patient Understanding Using Teach-Back
- Patient-Reported Outcome Measures
- Ability To Provide Useful Analytics
- No Dedicated Funding/Resources
- Is The Patient Ready To Engage?
- Myths/Misperceptions Of PFE
- Understandable Language
- Fear Of Reputation Drop
- Managing Expectations
- Standardized Methods
- Lack Of ROI Evidence
- Telephonic Discussions
- Family Preparedness
- Medical Paternalism
- Contact Information
- Not Enough Time
- Response
- Willingness
- Informed
- Cost