

Draft Technical Brief

Number xx

Strategies for Patient, Family, and Caregiver Engagement

Prepared for:

Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov

This information is distributed solely for the purposes of predissemination peer review. It has not been formally disseminated by the Agency for Healthcare Research and Quality. The findings are subject to change based on the literature identified in the interim and peer-review/public comments and should not be referenced as definitive. It does not represent and should not be construed to represent an Agency for Healthcare Research and Quality or Department of Health and Human Services (AHRQ) determination or policy.

Contract No. To be added to the final version.

Prepared by:

To be added to the final version.

Investigators:

To be added to the final version.

AHRQ Publication No. xx-EHCxxx
<Month Year>

This report is based on research conducted by the XXXXX Evidence-based Practice Center (EPC) under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. XXX-20XX-XXXXX). 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 decisionmakers—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.

This report is made available to the public under the terms of a licensing agreement between the author and the Agency for Healthcare Research and Quality. This report may be used and reprinted without permission except those copyrighted materials that are clearly noted in the report. Further reproduction of those copyrighted materials is prohibited without the express permission of copyright holders.

AHRQ or U.S. Department of Health and Human Services endorsement of any derivative products that may be developed from this report, such as clinical practice guidelines, other quality enhancement tools, or reimbursement or coverage policies may not be stated or implied.

Persons using assistive technology may not be able to fully access information in this report. For assistance contact EPC@ahrq.hhs.gov.

Suggested citation: <Authors>. **Strategies for Patient, Family and Caregiver Engagement** . Technical Brief <#>. (Prepared by the <EPC Name> Evidence-based Practice Center under Contract No. <##>.) AHRQ Publication No. XX-EHCXXX-EF. Rockville, MD: Agency for Healthcare Research and Quality. <Month Year>. Posted final reports are located on the Effective Health Care Program [search page](#). <doi>.

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.

Gopal Khanna, M.B.A.
Director
Agency for Healthcare Research and Quality

Arlene Bierman, M.D., M.S.
Director
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality

Stephanie Chang, M.D., M.P.H.
Director
Evidence-based Practice Center Program
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality

Elise Berliner, PhD
Task Order Officer
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality

Acknowledgments

The authors gratefully acknowledge the following individuals for their contributions to this project:

To be added to the final version.

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.

The list of Key Informants who provided input to this report follows:

To be added to the final version.

Peer Reviewers

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.

The list of Peer Reviewers follows:

To be added to the final version.

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 October 2019 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 grey 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, five on the health system level, and none on the community level. Eight reviews (five with studies having comparison groups, and 3 with studies lacking comparison groups) reported implementation outcomes. The reviews included studies per review ranging 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 decisionmaking (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 multi-component 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 decisionmaking also described multi-component 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.

Contents

Introduction.....	1
Background.....	1
Guiding Questions	4
Methods.....	5
Discussions with Key Informants	5
Published Literature	5
Grey Literature.....	7
Results.....	8
Results of the Key Informant Interviews	8
Results of the Published Literature Search	9
Guiding Question 1	12
Overview of Direct Patient Care Strategies (Guiding Question 1.a-1.c).....	12
Direct Patient Care Strategies – In Reviews including Adults with Chronic Conditions (Guiding Question 1.a-1.c)	15
Direct Patient Care Strategies – In Reviews including Children with Chronic Conditions (Guiding Question 1.a-1.c)	22
Direct Patient Care Strategies – In Reviews including both Adults and Children with Chronic Conditions (Guiding Question 1.a-1.c)	26
Implementation of Direct Patient Care Strategies (Guiding Question 1.d-1.f).....	31
Health System and Organization Strategies – In Patients with Chronic Conditions (Guiding Question 1.a-1.c).....	31
Implementation of Health System and Organization Strategies – In Patients with Chronic Conditions (Guiding Question 1.d-1.f)	32
Community/Policy Engagement Strategies	33
Results from the Grey Literature	33
Guiding Question 2	34
Discussion and Implications	38
Conclusions.....	41
References.....	43

Tables

Table 1. Key Informant interview questions.....	5
Table 2. Inclusion and exclusion criteria	6
Table 3. Key Informants’ expertise	8
Table 4. Key messages from the Key Informants.....	9

Figures

Figure 1. Patient, family, and caregiver engagement conceptual framework.....	3
Figure 2. Search flow diagram for systematic review	10
Figure 3. Search flow diagram for original studies.....	11
Figure 4. Number of systematic reviews addressing direct patient care and family engagement strategies, by age group (n=126).....	13
Figure 5. Intervention modality by direct patient engagement strategies (self-management support, shared decisionmaking, or other) in systematic reviews (n=126).....	14

Figure 6. Systematic reviews on direct patient care strategies, by year and focus on technology (n=126).....	15
Figure 7. Chronic medical conditions targeted in systematic reviews addressing direct patient care patient and family engagement strategies, among adults (n=96).....	16
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).....	18
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).....	20
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).....	23
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)...	25
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).....	26
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).....	28
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).....	29
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).....	30
Figure 16. Map of the evidence on patient and family engagement strategies by level of engagement.....	36
Figure 17. Map of the evidence on direct patient and family engagement strategies by reported level of benefit for different types of outcomes.....	37

Appendixes

- Appendix A. Search Strategies
- Appendix B. Evidence Tables
- Appendix C. Grey literature search
- Appendix D. List of Excluded Studies -Systematic Reviews
- Appendix E. List of Excluded Studies - Original Articles
- Appendix F. List of Original Articles for Direct Patient Care Strategy
- Appendix G. Word Clouds

Evidence Summary

Key Points

- The majority of systematic reviews on patient and family engagement for chronic conditions focused on direct patient care engagement strategies.
- The direct patient care engagement strategies most commonly included team-based care to support patient self-management, patient-provider communication using shared decisionmaking, 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 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, without 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 October 2019. 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, five on the health system level, and none on the community level. Eight reviews (five with studies having comparison groups, and 3 with studies lacking comparison groups) reported implementation outcomes. The reviews included a large number of studies (4111 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 3 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 decisionmaking (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 decisionmaking. Very few reviews focused on patients with multiple chronic conditions.

Self-management support strategies were mostly tested within multi-component 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, using 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 (HRQOL) 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 decisionmaking reviews described multi-component 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. Among 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 level 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 and 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 engagement refers to the efforts made by health care providers to help activate patients and their families or caregivers to manage their own health care.¹ The widely applied and accepted Chronic Care Model emphasizes the need for both an “informed activated patient” and a “prepared and proactive team” to improve patient outcomes.^{2,3} Multiple studies have demonstrated that activated patients have better health outcomes and lower utilization of emergency health care services.⁴ Conversely, low levels of patient engagement in health care are associated with significant, serious, or life-threatening adverse events.⁵

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.⁶ Self-management education and support interventions have also improved outcomes and function among patients with single and multiple chronic diseases.⁷⁻¹³

Despite the benefits of patient engagement (i.e., leading toward patient activation), not all patients have the capacity to be active 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.^{14, 15}

Clinicians and healthcare systems have key roles in patient and family engagement.¹⁶ Many strategies try to improve clinicians’ communication skills and shared decisionmaking techniques,¹⁷⁻²¹ in part because clinicians use complicated medical jargon, limiting patients’ understanding of their care.²² Communication studies show that clinicians quickly interrupt patients, allowing less opportunity for listening to concerns and building rapport.²³ 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.^{24, 25} 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).^{17-21, 26, 27}

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.^{16, 28, 29} Part of the motivation was the Patient Protection and Affordable Care Act (2010), which tied Medicare reimbursements with scores on a patient experience survey.³⁰ 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.²⁸ 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.^{31, 32} 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.³³⁻³⁶ 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.³⁷ A more recent review identified process improvements, but few studies examined clinical outcomes.³⁸

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 decisionmaking by health systems on which engagement strategies to deploy to improve outcomes.

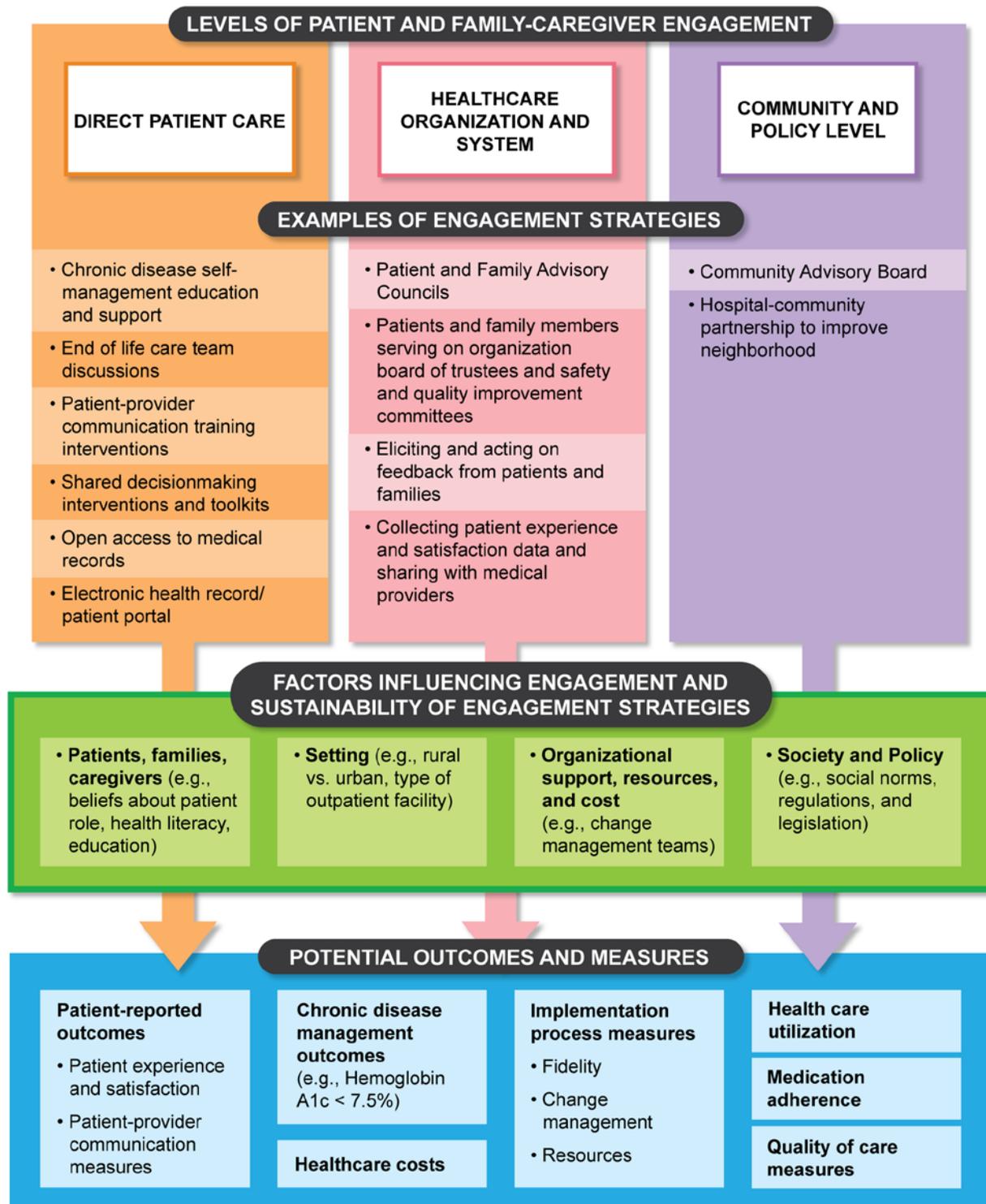
Conceptual Framework

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**).³⁹ 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 — direct care, organizational design and governance, and policymaking — to improve health and health care.”³⁹ We applied the adapted framework to create an evidence map displaying the evidence for patient and family engagement strategies.³⁹

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 decisionmaking, and communication strategies). 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 (e.g., a hospital-neighborhood partnership to address community’s concerns).

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. 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 grey or published literature.

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

Table 1. Key Informant interview questions

<p>From your experience or clinical practice, please identify an example of a patient, family or family engagement strategy.</p> <p>We will ask you to discuss this strategy on the call and consider some of these aspects of the strategy:</p> <ul style="list-style-type: none">• 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? <p>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.).</p> <p>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).</p>

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 2 lists the eligibility criteria.

Table 2. 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 decisionmaking (e.g., palliative, end of life, or treatment decisionmaking) • 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) <p>Include strategies that engage patients, caregivers, and families on Level 3 and above of the HIMSS patient engagement framework</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.
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>	No comparison group
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 • Implementation <ul style="list-style-type: none"> ○ Fidelity 	None

PICOTS	Include	Exclude
	<ul style="list-style-type: none"> ○ Sustainability ○ Barriers and facilitators ○ Cost/resources ○ Change management 	
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)	Non-US-based studies

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

Search, Study Selection, and Data Abstraction

Our search strategies are in Appendix A. We first searched PubMed and CINAHL from January 2015 through September 2019 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 September 2019 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 excluded original articles that had been captured in the systematic reviews. 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 will update the search while the Technical Brief is 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. The team summarized the findings from the systematic reviews based on the assessment by the reviews’ authors in their conclusions.

Grey Literature

We designed the grey 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 grey 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 one-hour interviews with nine Key Informants. Table 3 describes the expertise of the Key Informants.

Table 3. 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

Table 4 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.

Table 4. Key messages from the Key Informants

Patient engagement strategies
Patient portals
Advanced care planning
Shared decisionmaking
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
Using patient advice
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 decisionmaking 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 providers 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.

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.

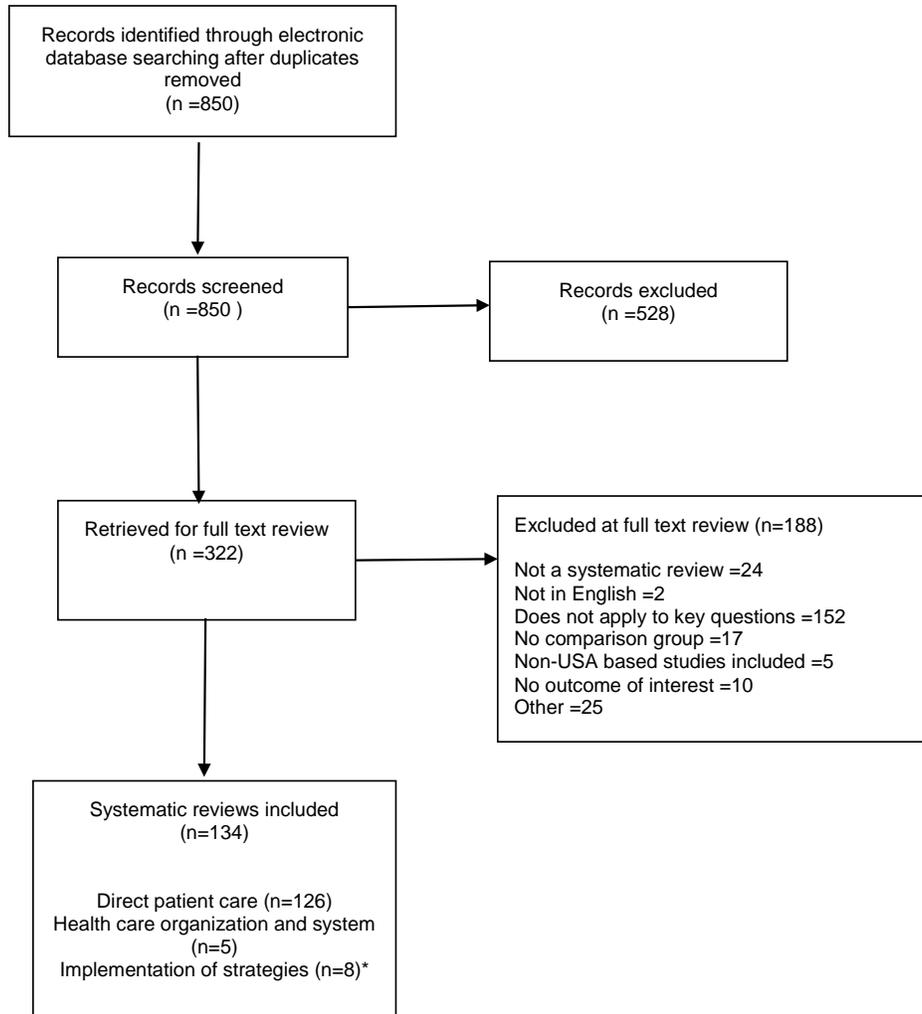
Results of the Published Literature Search

Figure 2 shows the search flow diagram for our main search focused on systematic reviews. The search for systematic reviews identified 850 references published between 2015 and 2019. Title and abstract review selected 322 references for full text review. One hundred thirty-four systematic reviews met the eligibility criteria. 126 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. We identified 4 original studies focused on these strategies. A listing of excluded studies is included in Appendix E.

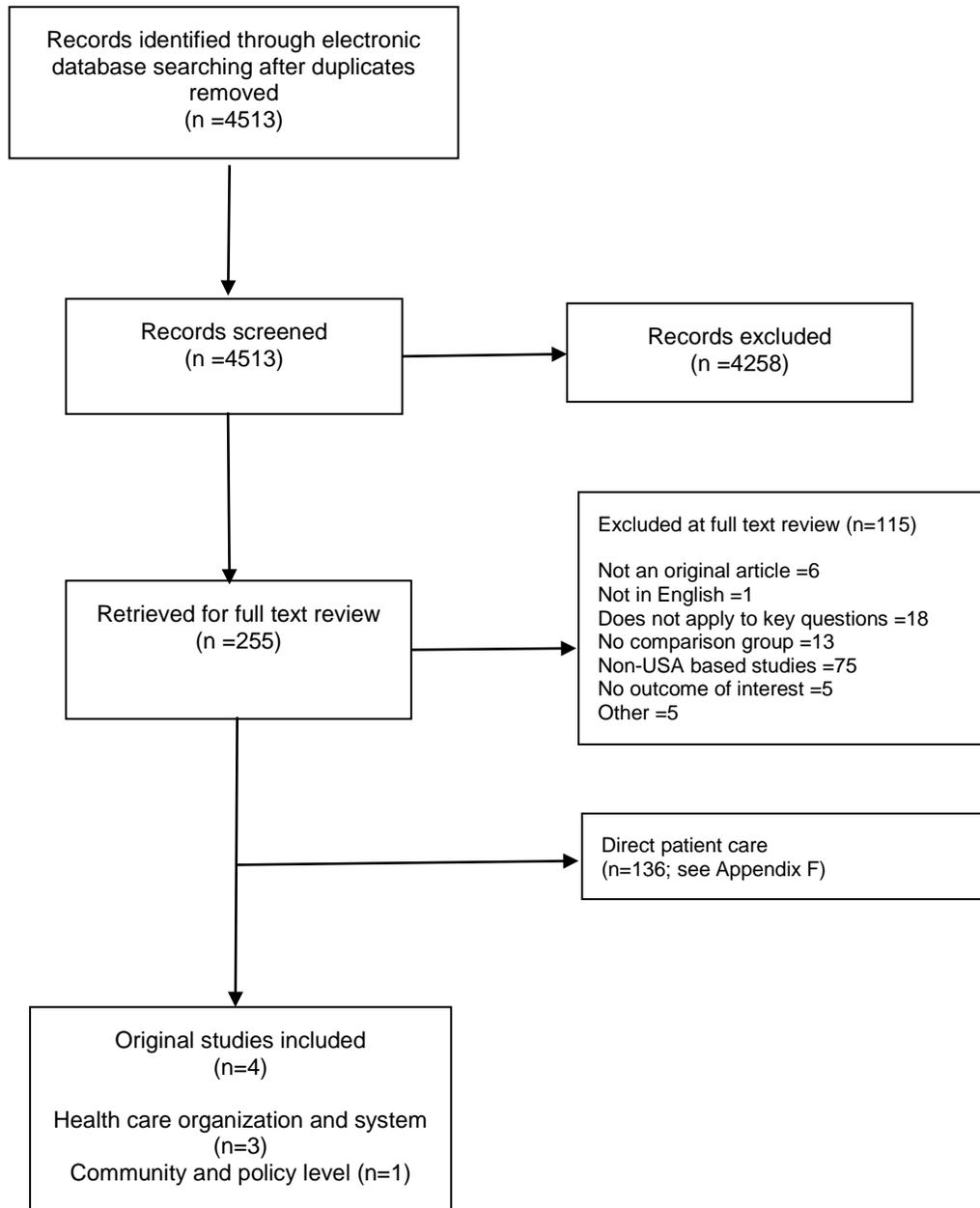
Figure 2. Search flow diagram for systematic review



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

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

Figure 3. Search flow diagram for original studies



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 decisionmaking, 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 decisionmaking/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 decisionmaking 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)

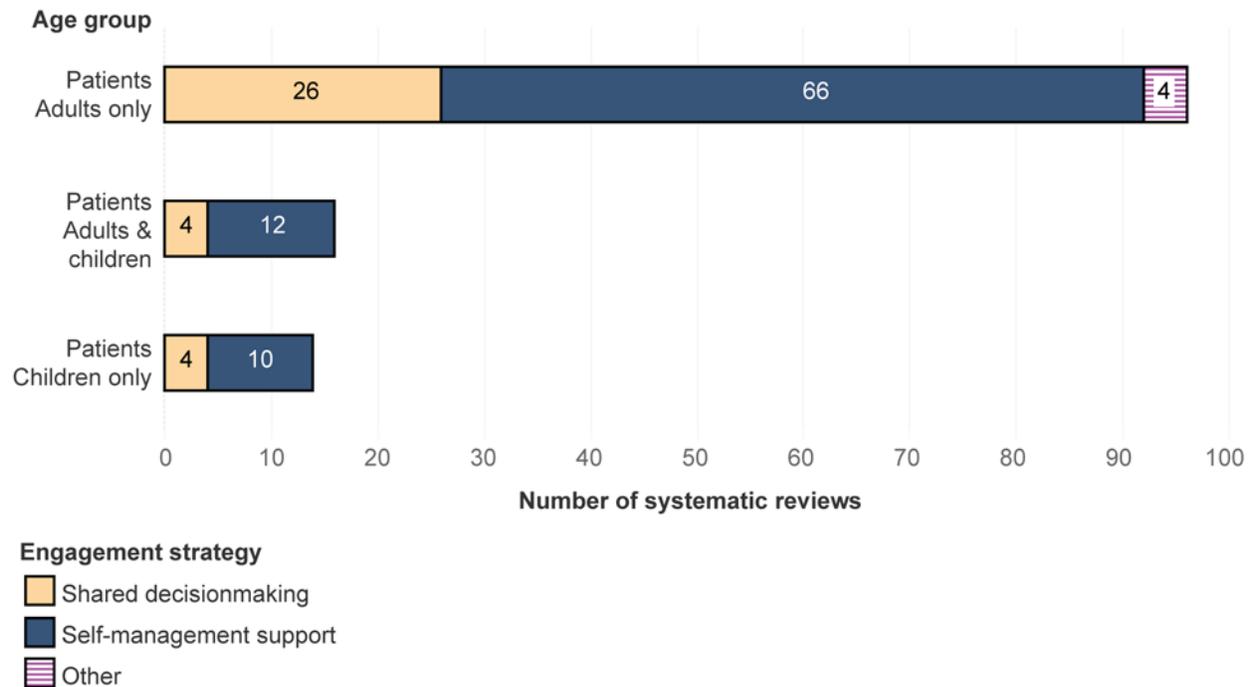


Figure 5 shows the modality (e.g., types of teams, tools or technology) for each type of direct care engagement strategy across all 126 systematic reviews. Across all age groups, the majority of reviews focused on self-management support, and among those, most reviews included nurses or case managers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

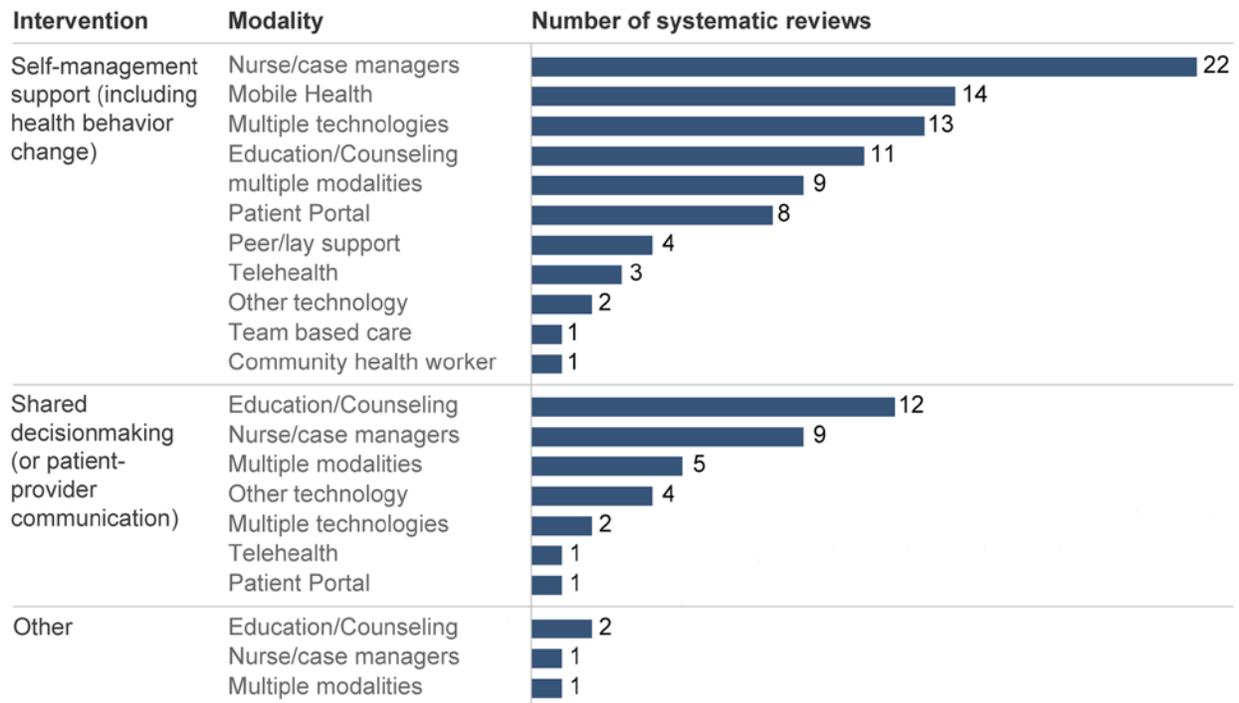
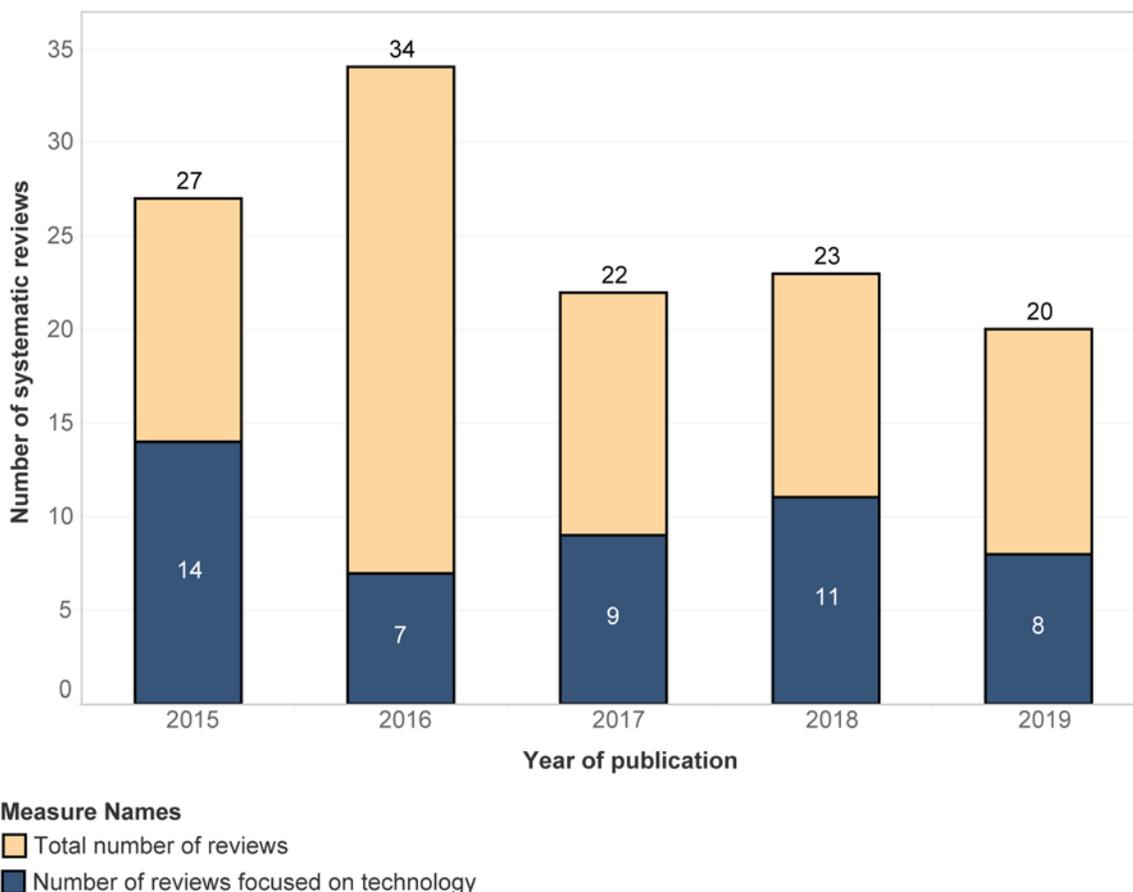


Figure 6 shows the distribution of reviews by year of publication and the number of reviews focused on technology (e.g., mobile health, electronic health record). We described the reviews that assessed the role of the patient portal, electronic health record, or mobile health within their respective 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 decisionmaking or enhanced patient-provider communication. Four reviews focused on other direct patient care engagement strategies. (Appendix B and Figure 4).

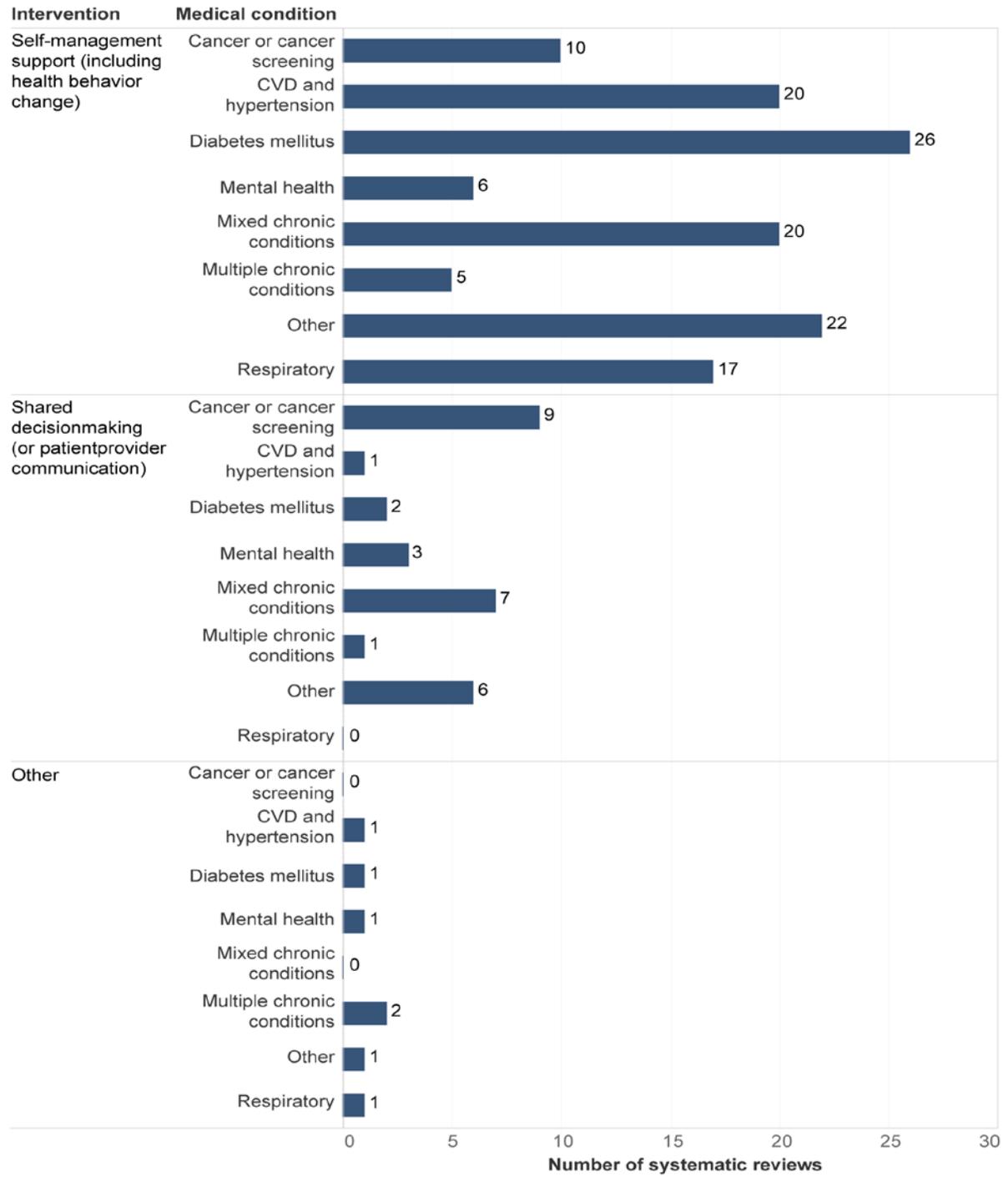
Self-management support

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)



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.⁴⁰⁻⁴⁶

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)

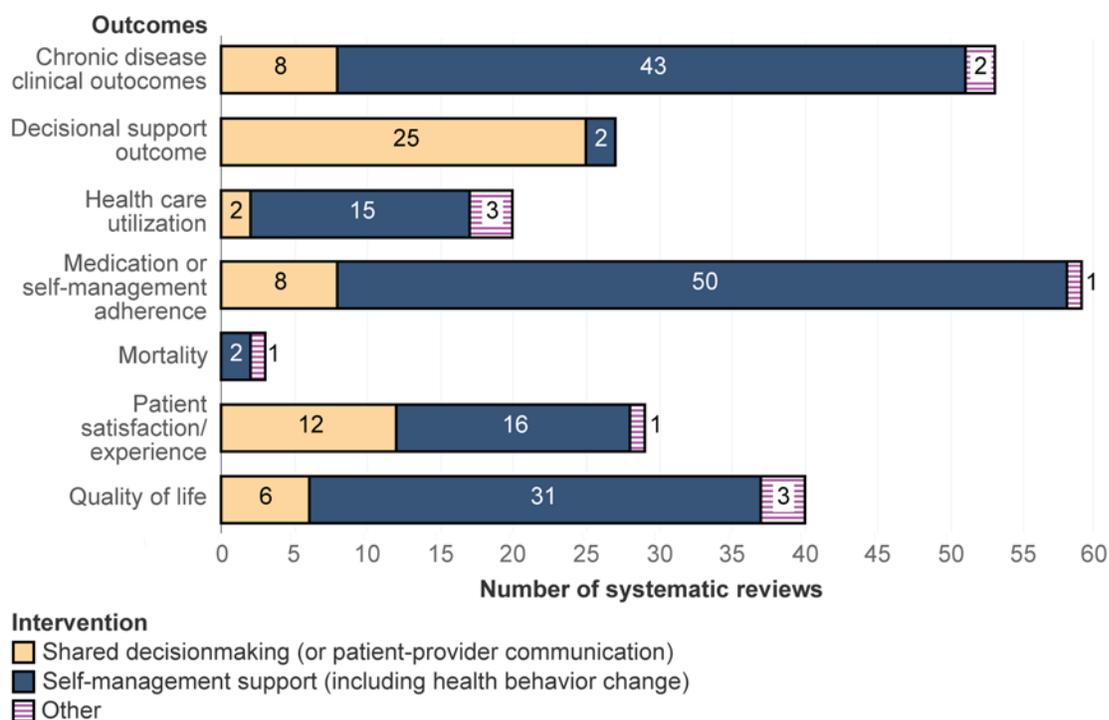


Figure 9 shows the findings by strategy. While 40 percent of the systematic reviews showed definite positive effects, 28 percent showed potential benefits, and 28 percent could not make any conclusions about benefit. No reviews reported any harm.

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,⁴⁷⁻⁵⁰ and one showed cost benefits for educational support interventions.⁵¹ 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.⁵²⁻⁵⁴ 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.⁵² Out of three systematic reviews focused on self-management support for cardiovascular disease, one showed no benefits⁵⁵ and two showed mixed findings.^{56, 57} Self-management interventions showed promising benefits for improving overall risk factor control among patients with stroke.⁵⁸ 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.⁵⁹

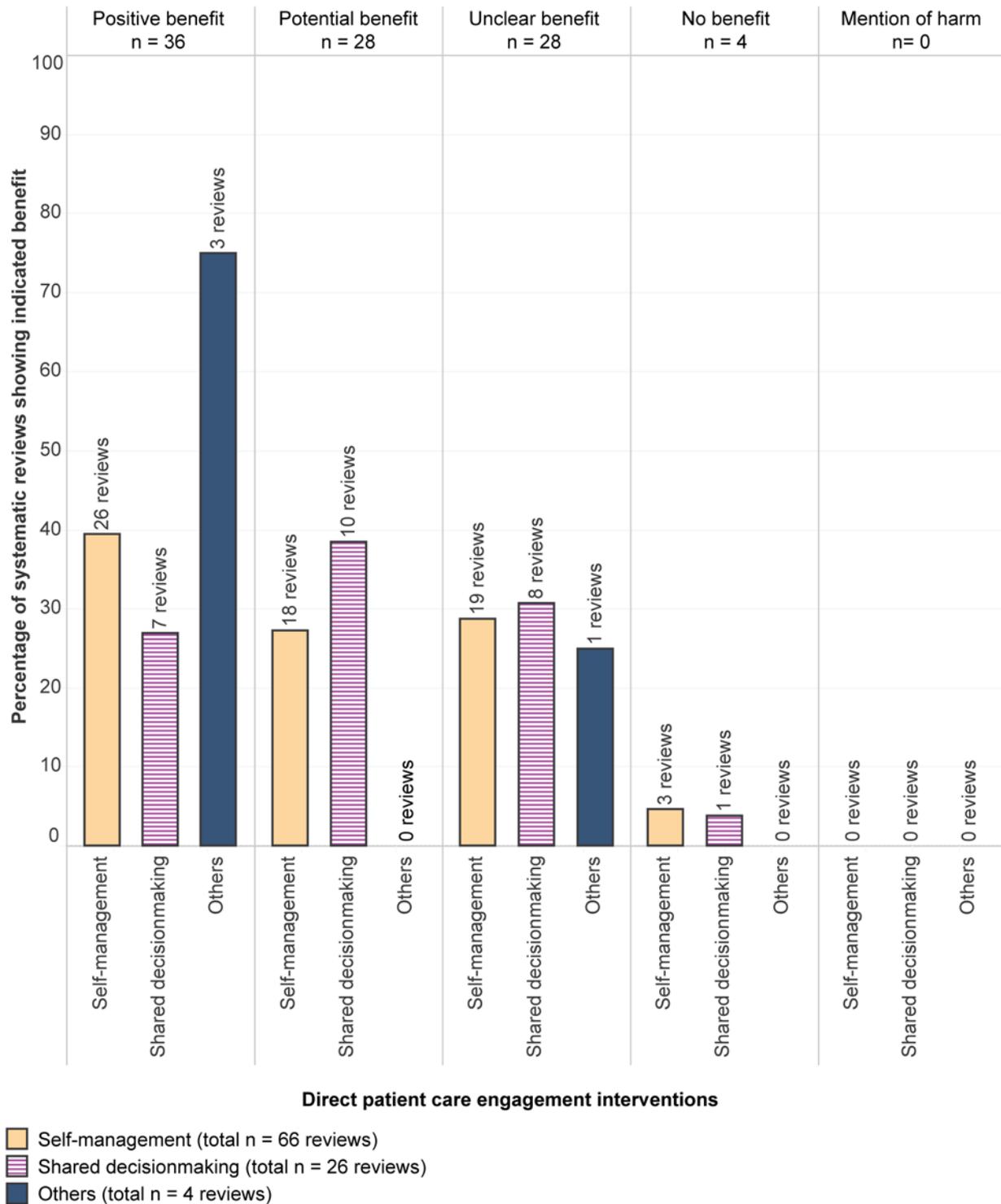
Two large systematic reviews showed benefits to low-income, underserved, and racial and ethnic minority patients from interventions delivered by community health workers, specifically

in the area of diabetes control, hypertension, and cancer screening behaviors.^{47, 60} 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.^{61, 62}

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.⁶³

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,⁶⁴ 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.⁶⁵ Among the eight systematic reviews focused on patient portals as engagement modality, one study focused on a clinical outcome (hemoglobin A1c⁴⁶) 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.⁴⁶

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

Shared Decisionmaking or Patient-Provider Communication

We identified 26 systematic reviews evaluating shared decisionmaking or patient-provider communication engagement strategies for adults with chronic disease (Appendix B). The systematic reviews that evaluated shared decisionmaking or patient-provider communication included between 4 to 120 studies each (with a range of 1 to 105 RCTs). The shared decisionmaking 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 decisionmaking outcomes in patients with psychosis (Figure 7).⁶⁶

Most shared decisionmaking 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.⁶⁷ This review also evaluated whether studies had considered the health literacy of their patient populations, such as adapting tools for lower literacy patients.⁶⁷ Most interventions included guidance and coaching for patients and training for physicians, as well as education for patients.⁶⁷ Two systematic reviews specifically evaluated shared decisionmaking engagement strategies for advanced care planning.^{68, 69} The systematic review by Vermunt and colleagues focused on collaborative goal setting for older patients with chronic diseases⁶⁸ 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.^{45, 70} One systematic review focused on patient engagement using an inpatient portal for communication,⁴⁵ and the other review focused on the outpatient clinical setting.⁷⁰

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 decisionmaking process. Few reviews reported on clinical outcomes. The systematic review by Kashaf and colleagues reported on shared decisionmaking among patients with type 2 diabetes and showed a lack of association with shared decisionmaking and outcomes of glycemic control, patient satisfaction, quality of life, medication adherence, or trust in physician.⁷¹ 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 decisionmaking 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,^{72, 73} advanced care planning,⁷⁴ and specific educational programming for patients undergoing peritoneal dialysis.⁷⁵

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).^{72, 73} 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,⁷² 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.

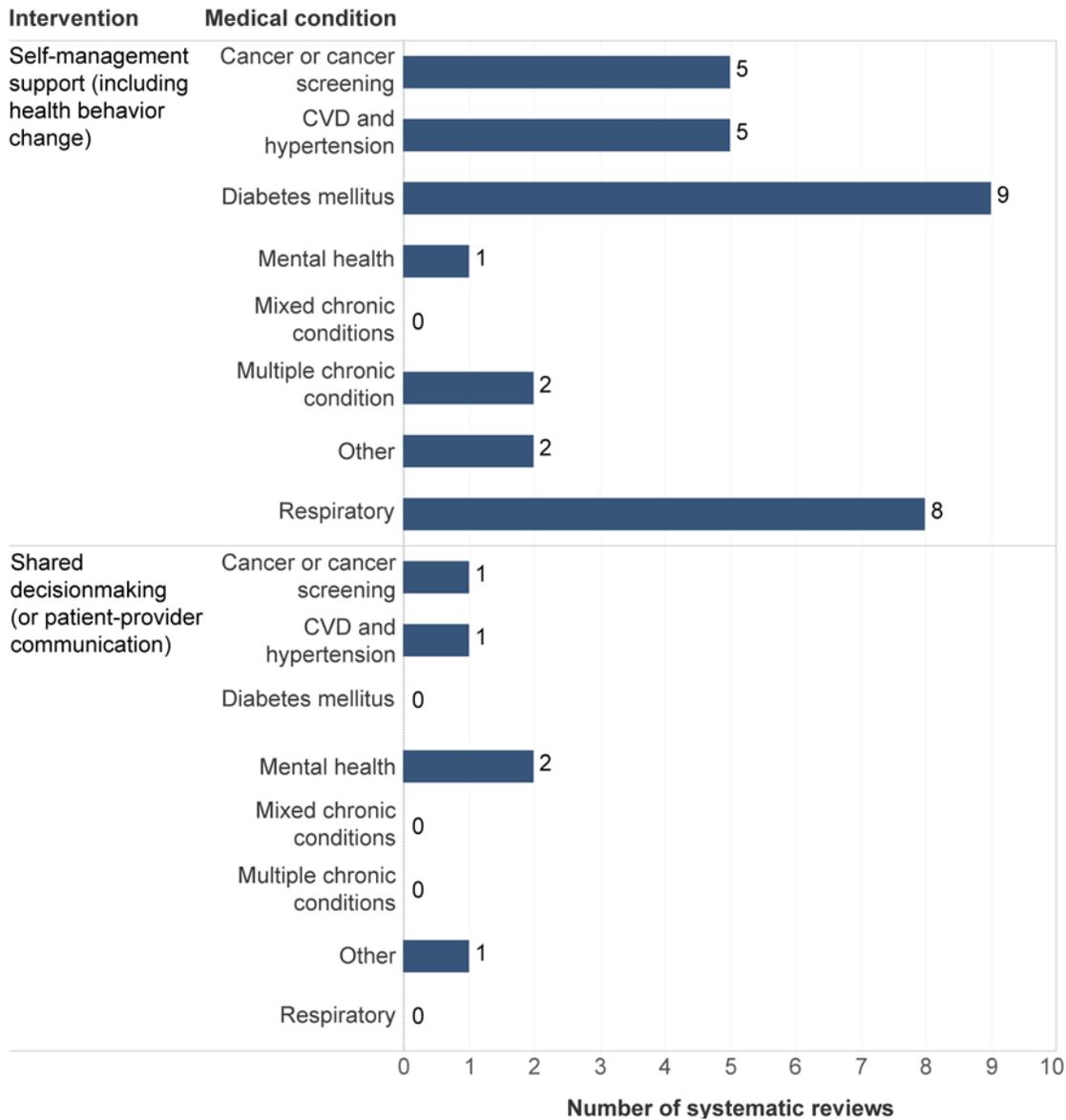
A Cochrane review by Coulter and colleagues examined 19 studies (16 RCTs) focused on advanced care planning for adults with long-term or chronic health conditions. The engagement interventions included a variety of tools to facilitate goal setting and action planning, including patient information packets (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.⁷⁴

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);⁷⁶ six on children and adolescents (0 to 18 years of age);⁷⁷⁻⁸² one on adolescents and young adults (11 to 25 years of age);⁸³ and, six on children, adolescents, and young adults (0 to 28 years of age).⁸⁴⁻⁸⁹ 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)^{76, 77, 79, 84-89} and asthma (8 reviews),^{77, 79, 84-89} followed by cystic fibrosis (5 reviews),^{76, 77, 84-86} cancer (5 reviews),^{77, 79, 86-88} and blood disorders (4 reviews).^{77, 79, 82, 86} Five systematic reviews included studies with family caregivers (i.e., parents/guardians),^{77, 79, 80, 82, 89} including one in which caregivers were the primary population of interest.⁷⁷ 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,^{77, 84, 87} two focused on strategies primarily used in the clinic setting,^{80, 82} three reported on strategies primarily used in the inpatient setting,^{76, 79, 83} and four focused on strategies used in multiple settings.^{85, 86, 88, 89} Three reviews included school and/or camp settings.^{85, 86, 89}

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

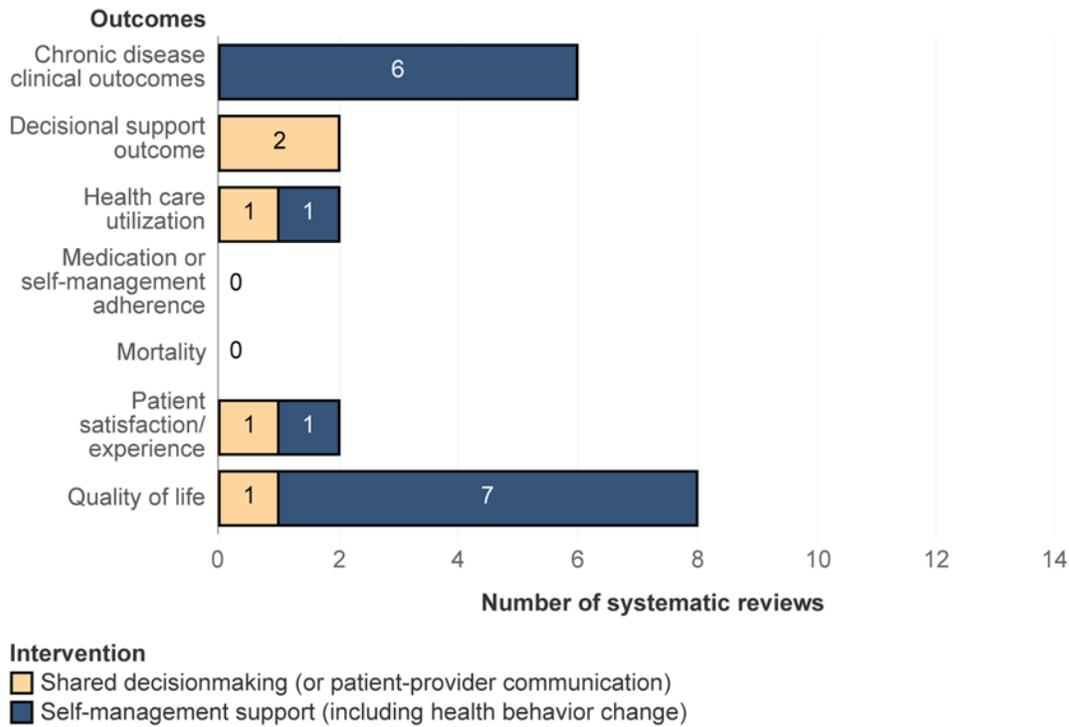
In the 14 systematic reviews of direct patient care engagement strategies in children and adolescents, the only engagement strategies evaluated were self-management support (10 reviews) and shared decisionmaking (4 reviews) (Figure 5). Three reviews evaluated self-management engagement strategies in the context of transitions of care, including team-based care, education/coaching sessions or counseling, and peer/lay-support.^{76, 79, 83} 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.⁸⁸

Among the four systematic reviews in children and adolescents that evaluated shared decisionmaking strategies, two reported on interventions with education/coaching sessions and decision aids.^{80, 82} The systematic review by Cheng and colleagues examined the use of shared decisionmaking in children and adolescents with mental health disorders. Most of the RCTs included in the review showed that parents using shared decisionmaking with providers had lower decisional conflict, and more engagement with treatment, and more of the parents' priorities were addressed.⁸⁰ Wyatt and colleagues also demonstrated a significant reduction in decisional conflict in a meta-analysis of nine studies that contained a heterogenous population of children with and without chronic disease.⁸²

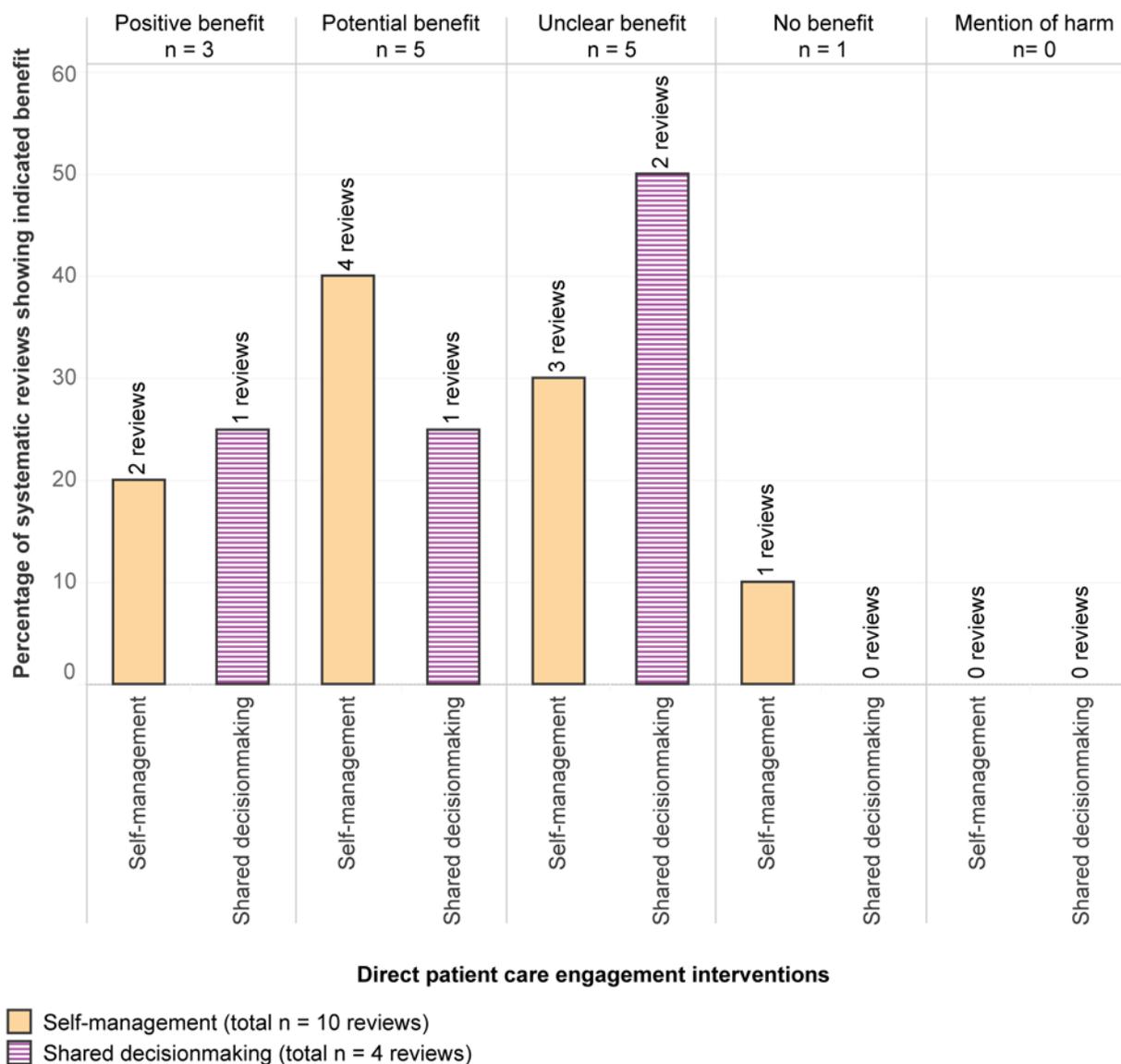
The 14 systematic reviews of direct patient care engagement strategies in children and adolescents reported on the following engagement outcomes: quality of life (8 reviews), medication or self-management adherence measures (7 reviews), and chronic disease clinical outcomes (6 reviews) (Figure 11). Two 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.⁷⁷ 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.⁷⁹ 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,^{76, 87, 89} one described no benefit,⁸⁴ and two did not report any findings.^{78, 81} 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

Direct Patient Care Strategies – In Reviews including both Adults and Children with Chronic Conditions (Guiding Question 1.a-1.c)

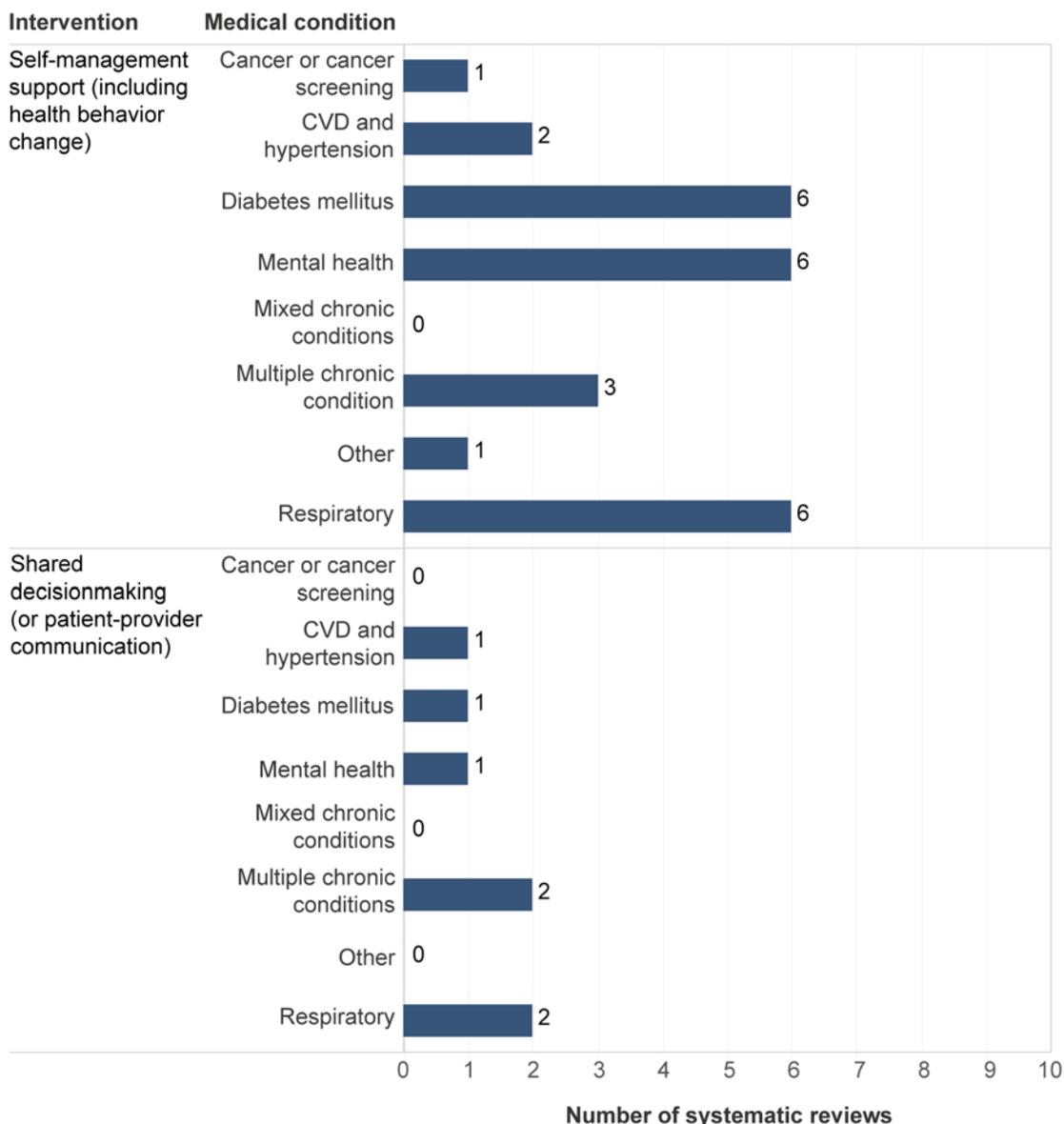
We identified 16 systematic reviews evaluating direct patient care engagement strategies that included children, adolescents, and adults with chronic disease. Overall, this increased the total number of reviews that included studies in pediatric populations to 30. However, given distinctions in eligibility 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 decisionmaking. 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)⁹⁰⁻⁹⁵ and diabetes (3 reviews)⁹⁶⁻⁹⁸ were the most frequently studied. Four reviews included family members or caregivers,^{94, 98-100} but only the systematic review by Chi and colleagues identified caregivers as their target population.¹⁰⁰ 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.¹⁰⁰ In addition, two systematic reviews included one study each that centered on vulnerable populations (rural patients or incarcerated patients).^{96, 101}

Of the 16 reviews, engagement strategies primarily involved self-management support (13 reviews) and shared decisionmaking (4 reviews).^{94, 95, 102, 103} One review examined health literacy,¹⁰⁴ and one specifically mentioned advanced care planning.¹⁰³ Four reviews cited multiple engagement strategies.^{95, 97, 103, 104} Technology was the most frequently cited intervention modality (11 reviews). Nurses or case managers^{97, 98} and coaching/educational sessions^{94, 99} were examined in two reviews, each. Shared decisionmaking 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.¹⁰³ 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)

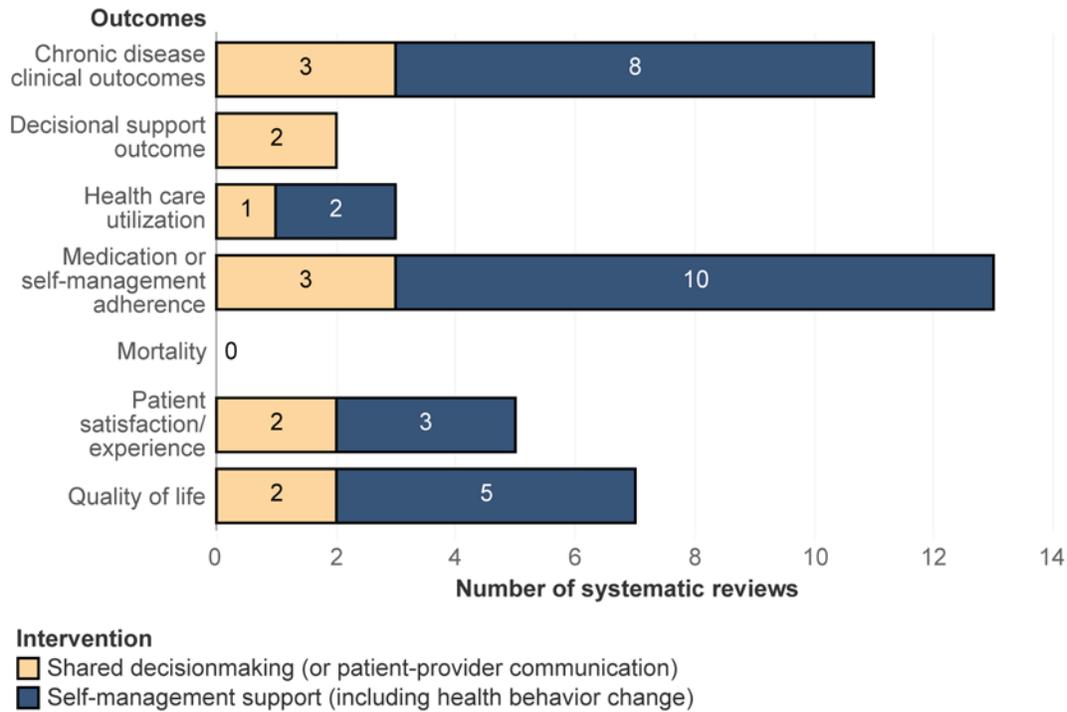


CVD =cardiovascular disease

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 colleagues⁹³ 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

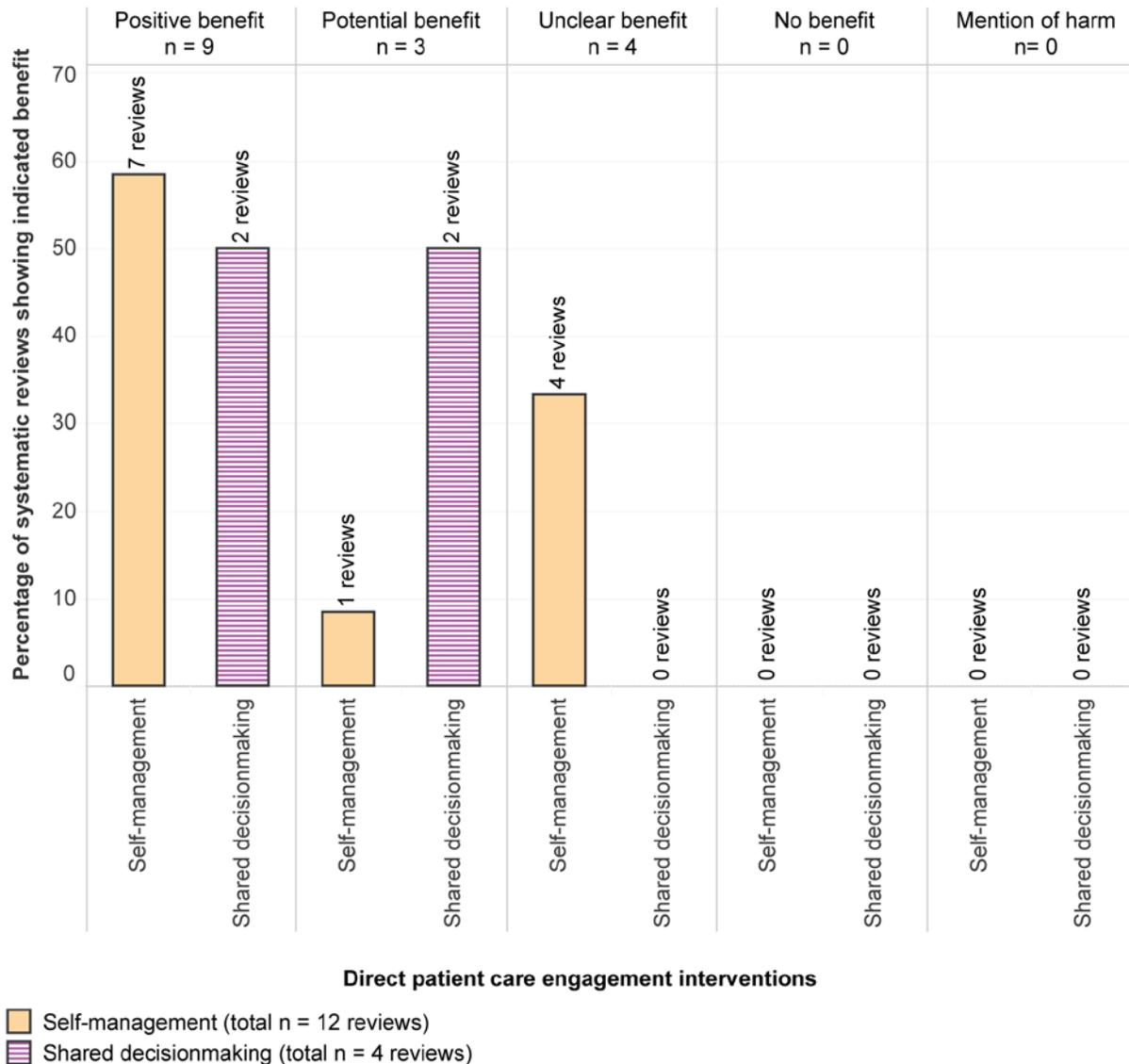
within the review examined pediatric patients and did not find any difference in control of their asthma between home telemonitoring and controls.

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.^{90, 93, 94, 101, 105} 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

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.^{43, 105, 106} The systematic review by Scholl and colleagues specifically addressed organizational- and system-level characteristics that influence implementation of shared decisionmaking strategies.¹⁰⁶ 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.^{43, 105} 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.⁴³ The systematic review by Kruse and colleagues also highlighted the costs associated with implementation of patient portals for patient engagement and communication.¹⁰⁵

In addition to the included systematic reviews, we identified three systematic reviews that reported on implementation outcomes.¹⁰⁷⁻¹⁰⁹ Systematic reviews by Anderson and Legare reported on communication (Anderson on end of life communication¹⁰⁸, and Legare on shared decisionmaking¹⁰⁹). 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.”¹⁰⁶ 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.¹⁰⁷

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

We identified five systematic reviews¹¹⁰⁻¹¹⁴ and three additional original articles^{90, 115, 116} that reported on patient and caregiver engagement at the health system level. The articles described specific strategies, facilitators and barriers to implementation,^{112, 113} and the impact of patient engagement on health care delivery and outcomes.¹¹⁰⁻¹¹⁴

The health system patient and caregiver engagement strategies reported in the five systematic reviews addressed a variety of chronic conditions, most commonly mental health,^{110, 112, 114} cancer,^{112, 114} diabetes mellitus,^{110, 112} and neurologic conditions,^{112, 114} as well as priority setting and improvement of care processes that were not disease-specific.^{110, 114} Patient and caregiver engagement strategies most often included patients and family members, but also included representatives of community-based organizations¹¹⁰ and other community members,¹¹⁴ “consumers,”¹¹¹ and “well members of the public.”¹¹³ Most systematic reviews examined engagement within a variety of health care settings,^{110-112, 114} 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.¹¹³

Patient and caregiver engagement strategies included patient and community advisory councils,^{110, 112-114} service as members of committees, participation in meetings or on project teams,¹¹²⁻¹¹⁴ forums and workshops to provide patients with skills to support engagement,^{111, 112} patients serving as instructors of trainees,¹¹¹ and patients providing consultative input (e.g., through surveys, focus groups, or interviews).^{112, 113}

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 advisors¹¹⁴ 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.”¹¹⁴ 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 colleagues¹¹² 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 councils¹¹⁰ 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.^{112, 113} Both of these systematic reviews included multiple patient and family engagement strategies, although one was limited to care delivered in hospital-based settings.¹¹³

Both reviews reported the importance of defining clear roles for patients and training of patients and providers or staff.^{112, 113} 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,¹¹⁵ and in a national collaborative study on patient and family collaboration in intensive care units.⁹⁰

Based on the barriers and facilitators in their systematic review,¹¹³ 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.¹¹³

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

Community/Policy Engagement Strategies

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.¹¹⁷ 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.¹¹⁷ We did not identify any articles that described implementation of community and policy engagement strategies.

Results from the Grey Literature: Innovative Patient and Family Engagement Strategies among Patients with Chronic Conditions

Appendix C summarizes the findings from the grey 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 grey 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.”¹¹⁴ Finally, tools for standardized measurement of patient engagement would facilitate evaluation of implementation success.¹¹⁰ Despite gaps in the evidence around health system strategies, in the grey 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.^{68, 69, 74, 103} 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.¹¹⁸ 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.¹¹⁸ 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, beyond patient satisfaction with care; 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

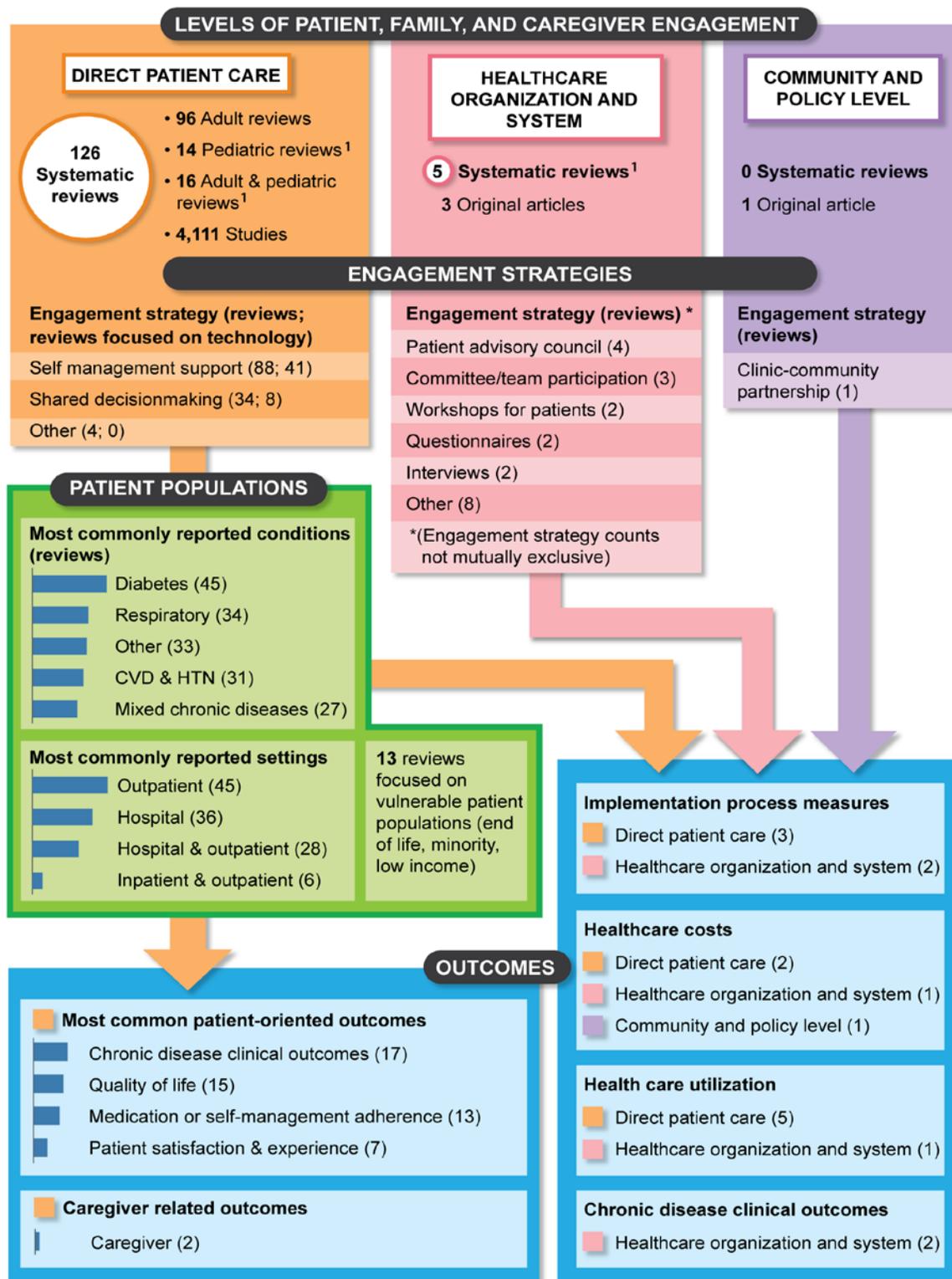
families in advanced care planning and end of life care; 4) develop patient portal and other technology tools that are adapted for patients with lower literacy or low technology skills to facilitate communication with medical providers; 5) measure cost-effectiveness of patient and caregiver engagement 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.

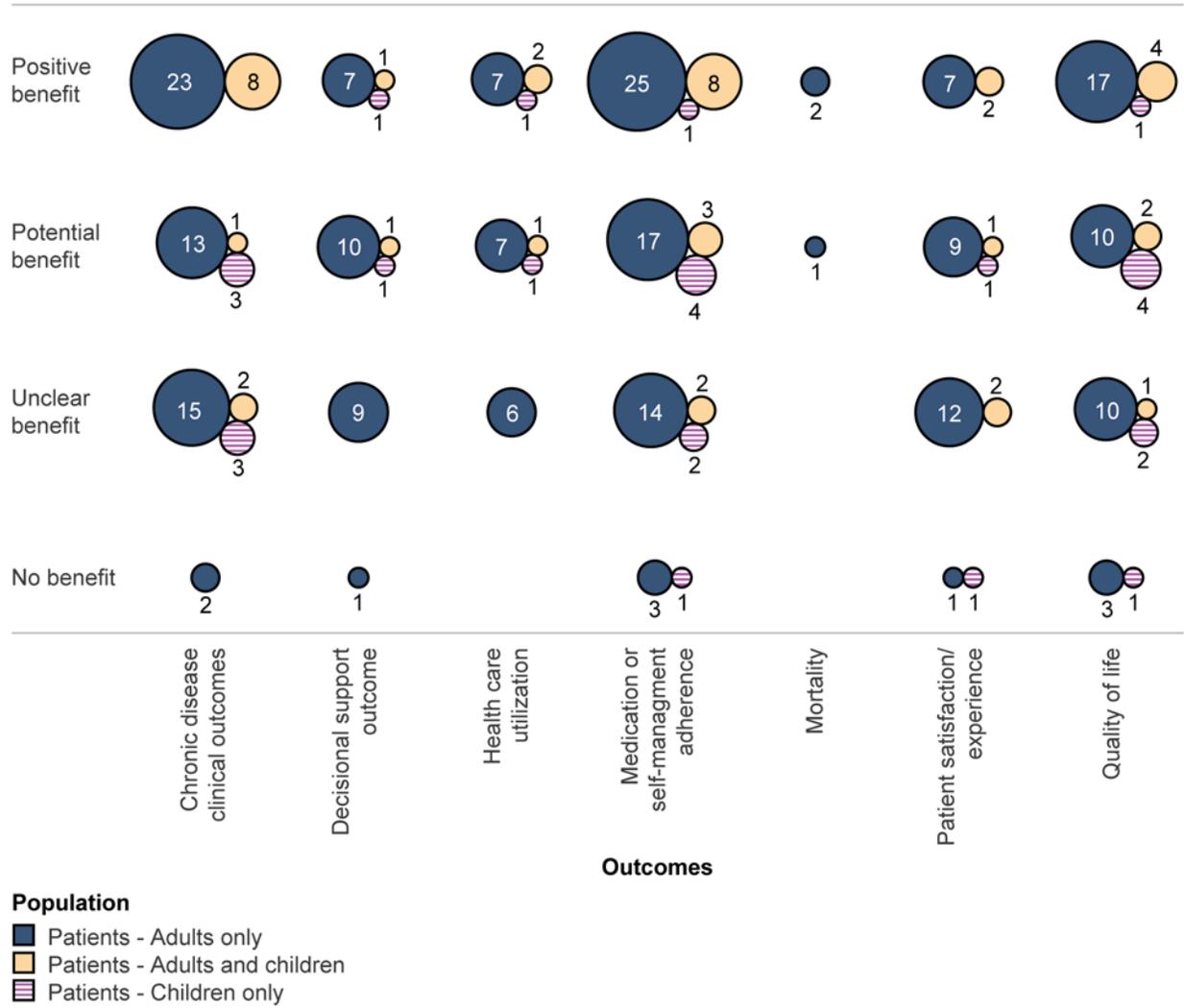
Finally, our evidence map highlights a need for both systematic review and original studies to examine implementation outcomes related to scaling and implementing direct and health system level engagement strategies. The learning health system needs to understand the fidelity, implementation, cost, and 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 decisionmaking), 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).³⁹ 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."³⁹ 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.²⁹ 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 decisionmaking, 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,^{110, 114} while three reviews examined system level patient and family engagement through a variety of other strategies, including participating in meetings, committees, and project teams,¹¹²⁻¹¹⁴ or providing consultative input through surveys, focus groups, or interviews.^{112, 113} 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. Overall, the health system reviews showed that patient and family advisory councils and having patients serve on committees are the most commonly studied strategies. 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.¹¹⁷

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 decisionmaking, 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 level of evidence (i.e., several large RCTs) included group-based educational programs to promote chronic disease self-management by peers and other healthcare professionals,¹¹⁹ web-based and short message service interventions for cancer survivors,⁵² promising telehealth programs to promote communication, self-monitoring and counseling,¹²⁰ as well as mobile health to promote weight loss.¹²¹ Among pediatric patients, the most promising and innovative direct-patient care engagement strategies included: eHealth tools for symptom control in adolescents with asthma;⁹¹ transitions of care support through combined care coordination and family education sessions at hospital discharge;⁷⁹ and shared decisionmaking with decision aids,⁸² especially for mental health treatment.⁸⁰ Importantly, these strategies required consideration of the child's age and developmental level, but also standard educational components as reported by Saxby and colleagues.⁸⁵

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.¹²² Like the Coulter review, we identified many patient and family engagement reviews focused on self-management support and education, as well as clinical decisionmaking through patient-provider communication strategies.¹²² 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,⁷⁰ 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.⁷⁰ 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.⁴⁶ 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.^{46, 123}

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. 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. 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.

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.”¹²⁴ 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.¹²⁵ 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

To address evidence gaps, 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,¹²⁶ reported on measurement and evaluation tools for the assessments of patient, public, consumer, and community engagement in organization-, community-, and system-level healthcare decisionmaking. 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).¹²⁶ 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. For example, 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 vulnerable populations, the role of family and caregivers is particularly relevant to efforts to improve engagement. 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. 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. In addition, 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. 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.

REFERENCES

1. Threnhauser S. OPEN MINDS -From Consumer Engagement To Consumer Activation -. 2018. <https://www.openminds.com/market-intelligence/executive-briefings/from-consumer-engagement-to-consumer-activation/>.
2. Von Korff M, Gruman J, Schaefer J, et al. Collaborative management of chronic illness. *Annals of internal medicine*. 1997 Dec 15;127(12):1097-102. doi: 10.7326/0003-4819-127-12-199712150-00008. PMID: 9412313.
3. Wagner EH, Bennett SM, Austin BT, et al. Finding common ground: patient-centeredness and evidence-based chronic illness care. *Journal of alternative and complementary medicine (New York, NY)*. 2005;11 Suppl 1:S7-15. doi: 10.1089/acm.2005.11.s-7. PMID: 16332190.
4. Remmers C, Hibbard J, Mosen DM, et al. Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes? *The Journal of ambulatory care management*. 2009 Oct-Dec;32(4):320-7. doi: 10.1097/JAC.0b013e3181ba6e77. PMID: 19888008.
5. Weingart SN, Zhu J, Chiappetta L, et al. Hospitalized patients' participation and its impact on quality of care and patient safety. *International journal for quality in health care : journal of the International Society for Quality in Health Care*. 2011 Jun;23(3):269-77. doi: 10.1093/intqhc/mzr002. PMID: 21307118.
6. Hibbard JH, Greene J, Tusler M. Improving the outcomes of disease management by tailoring care to the patient's level of activation. *The American journal of managed care*. 2009 Jun;15(6):353-60. PMID: 19514801.
7. Rost K, Nutting P, Smith JL, et al. Managing depression as a chronic disease: a randomised trial of ongoing treatment in primary care. *BMJ (Clinical research ed)*. 2002 Oct 26;325(7370):934. doi: 10.1136/bmj.325.7370.934. PMID: 12399343.
8. Lorig KR, Sobel DS, Stewart AL, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Medical care*. 1999 Jan;37(1):5-14. doi: 10.1097/00005650-199901000-00003. PMID: 10413387.
9. Greenfield S, Kaplan SH, Ware JE, Jr., et al. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *Journal of general internal medicine*. 1988 Sep-Oct;3(5):448-57. doi: 10.1007/bf02595921. PMID: 3049968.
10. Funnell MM, Brown TL, Childs BP, et al. National standards for diabetes self-management education. *Diabetes care*. 2012 Jan;35 Suppl 1:S101-8. doi: 10.2337/dc12-s101. PMID: 22187467.
11. Fitzpatrick SL, Schumann KP, Hill-Briggs F. Problem solving interventions for diabetes self-management and control: a systematic review of the literature. *Diabetes research and clinical practice*. 2013 May;100(2):145-61. doi: 10.1016/j.diabres.2012.12.016. PMID: 23312614.

12. Effing T, Monninkhof EM, van der Valk PD, et al. Self-management education for patients with chronic obstructive pulmonary disease. *The Cochrane database of systematic reviews*. 2007 Oct 17(4):Cd002990. doi: 10.1002/14651858.CD002990.pub2. PMID: 17943778.
13. Bayliss EA, Ellis JL, Steiner JF. Barriers to self-management and quality-of-life outcomes in seniors with multimorbidities. *Annals of family medicine*. 2007 Sep-Oct;5(5):395-402. doi: 10.1370/afm.722. PMID: 17893380.
14. Patient- and family-centered care and the pediatrician's role. *Pediatrics*. 2012 Feb;129(2):394-404. doi: 10.1542/peds.2011-3084. PMID: 22291118.
15. Conway JB, Edgman-Levitan S, Schlucter J, et al. Partnering with Patients and Families To Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future, A Work in Progress. Bethesda, MD: 2006. . 2006.
16. Institute of M. The National Academies Collection: Reports funded by National Institutes of Health. In: Olsen LA, Saunders RS, McGinnis JM, eds. *Patients Charting the Course: Citizen Engagement and the Learning Health System: Workshop Summary*. Washington (DC): National Academies Press (US) National Academy of Sciences.; 2011.
17. Entwistle VA, McCaughan D, Watt IS, et al. Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Quality & safety in health care*. 2010 Dec;19(6):e33. doi: 10.1136/qshc.2009.039743. PMID: 21127092.
18. Griffin SJ, Kinmonth AL, Veltman MW, et al. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. *Annals of family medicine*. 2004 Nov-Dec;2(6):595-608. doi: 10.1370/afm.142. PMID: 15576546.
19. Kaplan SH, Greenfield S, Ware JE, Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medical care*. 1989 Mar;27(3 Suppl):S110-27. doi: 10.1097/00005650-198903001-00010. PMID: 2646486.
20. Peat M, Entwistle V, Hall J, et al. Scoping review and approach to appraisal of interventions intended to involve patients in patient safety. *Journal of health services research & policy*. 2010 Jan;15 Suppl 1:17-25. doi: 10.1258/jhsrp.2009.009040. PMID: 20075123.
21. Schillinger D, Piette J, Grumbach K, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. *Archives of internal medicine*. 2003 Jan 13;163(1):83-90. doi: 10.1001/archinte.163.1.83. PMID: 12523921.
22. Castro CM, Wilson C, Wang F, et al. Babel babble: physicians' use of unclarified medical jargon with patients. *American journal of health behavior*. 2007 Sep-Oct;31 Suppl 1:S85-95. doi: 10.5555/ajhb.2007.31.supp.S85. PMID: 17931142.
23. Marvel MK, Epstein RM, Flowers K, et al. Soliciting the patient's agenda: have we improved? *Jama*. 1999 Jan 20;281(3):283-7. doi: 10.1001/jama.281.3.283. PMID: 9918487.
24. Brugge D, Edgar T, George K, et al. Beyond literacy and numeracy in patient provider communication: focus groups suggest roles for empowerment, provider attitude and language. *BMC public health*. 2009 Sep 21;9:354. doi: 10.1186/1471-2458-9-354. PMID: 19772555.

25. Wilson E, Chen AH, Grumbach K, et al. Effects of limited English proficiency and physician language on health care comprehension. *Journal of general internal medicine*. 2005 Sep;20(9):800-6. doi: 10.1111/j.1525-1497.2005.0174.x. PMID: 16117746.
26. Rao JK, Anderson LA, Inui TS, et al. Communication interventions make a difference in conversations between physicians and patients: a systematic review of the evidence. *Medical care*. 2007 Apr;45(4):340-9. doi: 10.1097/01.mlr.0000254516.04961.d5. PMID: 17496718.
27. Cooper LA, Roter DL, Carson KA, et al. A randomized trial to improve patient-centered care and hypertension control in underserved primary care patients. *Journal of general internal medicine*. 2011 Nov;26(11):1297-304. doi: 10.1007/s11606-011-1794-6. PMID: 21732195.
28. Herrin J, Harris KG, Kenward K, et al. Patient and family engagement: a survey of US hospital practices. *BMJ quality & safety*. 2016 Mar;25(3):182-9. doi: 10.1136/bmjqs-2015-004006. PMID: 26082560.
29. Nickel WK, Weinberger SE, Guze PA. Principles for Patient and Family Partnership in Care: An American College of Physicians Position Paper. *Annals of internal medicine*. 2018 Dec 4;169(11):796-9. doi: 10.7326/m18-0018. PMID: 30476985.
30. Millenson M, Macri J. Will the Affordable Care Act Move Patient-Centeredness to Center Stage? Timely Analysis of Immediate Health Policy Issues. 2002.
31. CMS CPCI. <https://innovation.cms.gov/initiatives/comprehensive-primary-care-initiative/>.
32. PCMH Standards and Guidelines. 2017. <https://www.kentuckyrec.com/wp-content/uploads/2017/10/02.-PCMH-Standards-and-Guidelines-2017-Edition-Version-2-9-30-17.pdf>.
33. Working With Patient and Families as Advisors (Implementation Handbook) - Agency for Healthcare Research and Quality. 2008.
34. Creating a Patient and Family Advisory Council: A Toolkit for Pediatric Practices - National Institute for Children's Health Quality. 2012.
35. CPC Patient and Family Engagement Resources from the National Partnership for Women & Families 2013. <https://innovation.cms.gov/Files/x/cpci-patientfamengresource.pdf>.
36. Moving Forward with Patient- and Family-Centered Care: Partnerships for Quality and Safety. 2019.
37. Crawford MJ, Rutter D, Manley C, et al. Systematic review of involving patients in the planning and development of health care. *BMJ (Clinical research ed)*. 2002 Nov 30;325(7375):1263. doi: 10.1136/bmj.325.7375.1263. PMID: 12458240.
38. Johnson KE, Mroz TM, Abraham M, et al. Promoting Patient and Family Partnerships in Ambulatory Care Improvement: A Narrative Review and Focus Group Findings. *Advances in therapy*. 2016 Aug;33(8):1417-39. doi: 10.1007/s12325-016-0364-z. PMID: 27352378.
39. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health affairs (Project Hope)*. 2013 Feb;32(2):223-31. doi: 10.1377/hlthaff.2012.1133. PMID: 23381514.

40. Price M, Bellwood P, Kitson N, et al. Conditions potentially sensitive to a personal health record (PHR) intervention, a systematic review. *BMC medical informatics and decision making*. 2015 Apr 18;15:32. doi: 10.1186/s12911-015-0159-1. PMID: 25927384.
41. Kruse CS, Bolton K, Freriks G. The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. *Journal of medical Internet research*. 2015 Feb 10;17(2):e44. doi: 10.2196/jmir.3171. PMID: 25669240.
42. Ammenwerth E, Hoerbst A, Lannig S, et al. Effects of Adult Patient Portals on Patient Empowerment and Health-Related Outcomes: A Systematic Review. *Studies in health technology and informatics*. 2019 Aug 21;264:1106-10. doi: 10.3233/shti190397. PMID: 31438096.
43. Dendere R, Slade C, Burton-Jones A, et al. Patient Portals Facilitating Engagement With Inpatient Electronic Medical Records: A Systematic Review. *Journal of medical Internet research*. 2019 Apr 11;21(4):e12779. doi: 10.2196/12779. PMID: 30973347.
44. Risling T, Martinez J, Young J, et al. Evaluating Patient Empowerment in Association With eHealth Technology: Scoping Review. *Journal of medical Internet research*. 2017 Sep 29;19(9):e329. doi: 10.2196/jmir.7809. PMID: 28963090.
45. Kelly MM, Coller RJ, Hoonakker PL. Inpatient Portals for Hospitalized Patients and Caregivers: A Systematic Review. *Journal of hospital medicine*. 2018 Jun 1;13(6):405-12. doi: 10.12788/jhm.2894. PMID: 29261819.
46. Kuo A, Dang S. Secure Messaging in Electronic Health Records and Its Impact on Diabetes Clinical Outcomes: A Systematic Review. *Telemedicine journal and e-health : the official journal of the American Telemedicine Association*. 2016 Sep;22(9):769-77. doi: 10.1089/tmj.2015.0207. PMID: 27027337.
47. Han HR, McKenna S, Nkimbeng M, et al. A Systematic Review of Community Health Center Based Interventions for People with Diabetes. *Journal of community health*. 2019 Jul 6. doi: 10.1007/s10900-019-00693-y. PMID: 31280431.
48. Levengood TW, Peng Y, Xiong KZ, et al. Team-Based Care to Improve Diabetes Management: A Community Guide Meta-analysis. *American journal of preventive medicine*. 2019 Jul;57(1):e17-e26. doi: 10.1016/j.amepre.2019.02.005. PMID: 31227069.
49. Zhao FF, Suhonen R, Koskinen S, et al. Theory-based self-management educational interventions on patients with type 2 diabetes: a systematic review and meta-analysis of randomized controlled trials. *Journal of advanced nursing*. 2017 Apr;73(4):812-33. doi: 10.1111/jan.13163. PMID: 27681948.
50. CADTH Rapid Response Reports. Patient- and Family-Centered Care Initiatives in Acute Care Settings: A Review of the Clinical Evidence, Safety and Guidelines. Ottawa (ON): Canadian Agency for Drugs and Technologies in Health Copyright (c) 2015 Canadian Agency for Drugs and Technologies in Health.; 2015.
51. Teljeur C, Moran PS, Walshe S, et al. Economic evaluation of chronic disease self-management for people with diabetes: a systematic review. *Diabetic medicine : a journal of the British Diabetic Association*. 2017 Aug;34(8):1040-9. doi: 10.1111/dme.13281. PMID: 27770591.

52. Kim AR, Park HA. Web-based Self-management Support Interventions for Cancer Survivors: A Systematic Review and Meta-analyses. *Studies in health technology and informatics*. 2015;216:142-7. PMID: 26262027.
53. Hammer MJ, Ercolano EA, Wright F, et al. Self-management for adult patients with cancer: an integrative review. *Cancer nursing*. 2015 Mar-Apr;38(2):E10-26. doi: 10.1097/ncc.000000000000122. PMID: 25692736.
54. Escriva Bouley G, Leroy T, Bernetiere C, et al. Digital health interventions to help living with cancer: A systematic review of participants' engagement and psychosocial effects. *Psycho-oncology*. 2018 Dec;27(12):2677-86. doi: 10.1002/pon.4867. PMID: 30152074.
55. Clarkesmith DE, Pattison HM, Khaing PH, et al. Educational and behavioural interventions for anticoagulant therapy in patients with atrial fibrillation. *The Cochrane database of systematic reviews*. 2017 Apr 5;4:Cd008600. doi: 10.1002/14651858.CD008600.pub3. PMID: 28378924.
56. Alessa T, Abdi S, Hawley MS, et al. Mobile Apps to Support the Self-Management of Hypertension: Systematic Review of Effectiveness, Usability, and User Satisfaction. *JMIR mHealth and uHealth*. 2018 Jul 23;6(7):e10723. doi: 10.2196/10723. PMID: 30037787.
57. Palacios J, Lee GA, Duaso M, et al. Internet-Delivered Self-management Support for Improving Coronary Heart Disease and Self-management-Related Outcomes: A Systematic Review. *The Journal of cardiovascular nursing*. 2017 Jul/Aug;32(4):E9-e23. doi: 10.1097/jcn.0000000000000392. PMID: 28107251.
58. Sakakibara BM, Kim AJ, Eng JJ. A Systematic Review and Meta-Analysis on Self-Management for Improving Risk Factor Control in Stroke Patients. *International journal of behavioral medicine*. 2017 Feb;24(1):42-53. doi: 10.1007/s12529-016-9582-7. PMID: 27469998.
59. Peytremann-Bridevaux I, Arditi C, Gex G, et al. Chronic disease management programmes for adults with asthma. *The Cochrane database of systematic reviews*. 2015 May 27(5):Cd007988. doi: 10.1002/14651858.CD007988.pub2. PMID: 26014500.
60. Kim K, Choi JS, Choi E, et al. Effects of Community-Based Health Worker Interventions to Improve Chronic Disease Management and Care Among Vulnerable Populations: A Systematic Review. *American journal of public health*. 2016 Apr;106(4):e3-e28. doi: 10.2105/ajph.2015.302987. PMID: 26890177.
61. Ko D, Bratzke LC, Roberts T. Self-management assessment in multiple chronic conditions: A narrative review of literature. *International journal of nursing studies*. 2018 Jul;83:83-90. doi: 10.1016/j.ijnurstu.2018.04.009. PMID: 29709734.
62. Smith SM, Wallace E, O'Dowd T, et al. Interventions for improving outcomes in patients with multimorbidity in primary care and community settings. *The Cochrane database of systematic reviews*. 2016 Mar 14;3:Cd006560. doi: 10.1002/14651858.CD006560.pub3. PMID: 26976529.
63. Thakkar J, Kurup R, Laba TL, et al. Mobile Telephone Text Messaging for Medication Adherence in Chronic Disease: A Meta-analysis. *JAMA internal medicine*. 2016 Mar;176(3):340-9. doi: 10.1001/jamainternmed.2015.7667. PMID: 26831740.

64. Deek H, Hamilton S, Brown N, et al. Family-centred approaches to healthcare interventions in chronic diseases in adults: a quantitative systematic review. *Journal of advanced nursing*. 2016 May;72(5):968-79. doi: 10.1111/jan.12885. PMID: 26751971.
65. Noonan MC, Wingham J, Dalal HM, et al. Involving caregivers in self-management interventions for patients with heart failure and chronic obstructive pulmonary disease. A systematic review and meta-analysis. *Journal of advanced nursing*. 2019 Aug 22. doi: 10.1111/jan.14172. PMID: 31441088.
66. Stovell D, Morrison AP, Panayiotou M, et al. Shared treatment decision-making and empowerment-related outcomes in psychosis: systematic review and meta-analysis. *The British journal of psychiatry : the journal of mental science*. 2016 Jul;209(1):23-8. doi: 10.1192/bjp.bp.114.158931. PMID: 27198483.
67. Stacey D, Legare F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *The Cochrane database of systematic reviews*. 2017 Apr 12;4:Cd001431. doi: 10.1002/14651858.CD001431.pub5. PMID: 28402085.
68. Vermunt N, Harmsen M, Westert GP, et al. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review. *BMC geriatrics*. 2017 Jul 31;17(1):167. doi: 10.1186/s12877-017-0534-0. PMID: 28760149.
69. Cardona-Morrell M, Benfatti-Olivato G, Jansen J, et al. A systematic review of effectiveness of decision aids to assist older patients at the end of life. *Patient education and counseling*. 2017 Mar;100(3):425-35. doi: 10.1016/j.pec.2016.10.007. PMID: 27765378.
70. Irizarry T, DeVito Dabbs A, Curran CR. Patient Portals and Patient Engagement: A State of the Science Review. *Journal of medical Internet research*. 2015 Jun 23;17(6):e148. doi: 10.2196/jmir.4255. PMID: 26104044.
71. Saheb Kashaf M, McGill ET, Berger ZD. Shared decision-making and outcomes in type 2 diabetes: A systematic review and meta-analysis. *Patient education and counseling*. 2017 Dec;100(12):2159-71. doi: 10.1016/j.pec.2017.06.030. PMID: 28693922.
72. Le Berre M, Maimon G, Sourial N, et al. Impact of Transitional Care Services for Chronically Ill Older Patients: A Systematic Evidence Review. *Journal of the American Geriatrics Society*. 2017 Jul;65(7):1597-608. doi: 10.1111/jgs.14828. PMID: 28403508.
73. Sendall M, McCosker L, Crossley K, et al. A structured review of chronic care model components supporting transition between healthcare service delivery types for older people with multiple chronic diseases. *Health information management : journal of the Health Information Management Association of Australia*. 2017 May;46(2):58-68. doi: 10.1177/1833358316681687. PMID: 27923916.
74. Coulter A, Entwistle VA, Eccles A, et al. Personalised care planning for adults with chronic or long-term health conditions. *The Cochrane database of systematic reviews*. 2015 Mar 3(3):Cd010523. doi: 10.1002/14651858.CD010523.pub2. PMID: 25733495.
75. Schaepe C, Bergjan M. Educational interventions in peritoneal dialysis: a narrative review of the literature. *International journal of nursing studies*. 2015 Apr;52(4):882-98. doi: 10.1016/j.ijnurstu.2014.12.009. PMID: 25616708.

76. Campbell F, Biggs K, Aldiss SK, et al. Transition of care for adolescents from paediatric services to adult health services. *The Cochrane database of systematic reviews*. 2016 Apr 29;4:Cd009794. doi: 10.1002/14651858.CD009794.pub2. PMID: 27128768.
77. Knafl KA, Havill NL, Leeman J, et al. The Nature of Family Engagement in Interventions for Children With Chronic Conditions. *Western journal of nursing research*. 2017 May;39(5):690-723. doi: 10.1177/0193945916664700. PMID: 27596106.
78. Malone H, Biggar S, Javadpour S, et al. Interventions for promoting participation in shared decision-making for children and adolescents with cystic fibrosis. *The Cochrane database of systematic reviews*. 2019 May 23;5:Cd012578. doi: 10.1002/14651858.CD012578.pub2. PMID: 31119726.
79. Hamline MY, Speier RL, Vu PD, et al. Hospital-to-Home Interventions, Use, and Satisfaction: A Meta-analysis. *Pediatrics*. 2018 Nov;142(5). doi: 10.1542/peds.2018-0442. PMID: 30352792.
80. Cheng H, Hayes D, Edbrooke-Childs J, et al. What approaches for promoting shared decision-making are used in child mental health? A scoping review. *Clinical psychology & psychotherapy*. 2017 Nov;24(6):O1495-o511. doi: 10.1002/cpp.2106. PMID: 28752631.
81. Coyne I, O'Mathuna DP, Gibson F, et al. Interventions for promoting participation in shared decision-making for children with cancer. *The Cochrane database of systematic reviews*. 2016 Nov 29;11:Cd008970. doi: 10.1002/14651858.CD008970.pub3. PMID: 27898175.
82. Wyatt KD, List B, Brinkman WB, et al. Shared Decision Making in Pediatrics: A Systematic Review and Meta-analysis. *Academic pediatrics*. 2015 Nov-Dec;15(6):573-83. doi: 10.1016/j.acap.2015.03.011. PMID: 25983006.
83. Clemente D, Leon L, Foster H, et al. Systematic review and critical appraisal of transitional care programmes in rheumatology. *Seminars in arthritis and rheumatism*. 2016 Dec;46(3):372-9. doi: 10.1016/j.semarthrit.2016.06.003. PMID: 27496195.
84. Low JK, Manias E. Use of Technology-Based Tools to Support Adolescents and Young Adults With Chronic Disease: Systematic Review and Meta-Analysis. *JMIR mHealth and uHealth*. 2019 Jul 18;7(7):e12042. doi: 10.2196/12042. PMID: 31322129.
85. Saxby N, Beggs S, Battersby M, et al. What are the components of effective chronic condition self-management education interventions for children with asthma, cystic fibrosis, and diabetes? A systematic review. *Patient education and counseling*. 2019 Apr;102(4):607-22. doi: 10.1016/j.pec.2018.11.001. PMID: 30471988.
86. Bal MI, Sattoe JN, Roelofs PD, et al. Exploring effectiveness and effective components of self-management interventions for young people with chronic physical conditions: A systematic review. *Patient education and counseling*. 2016 Aug;99(8):1293-309. doi: 10.1016/j.pec.2016.02.012. PMID: 26954345.
87. Majeed-Ariss R, Baidam E, Campbell M, et al. Apps and Adolescents: A Systematic Review of Adolescents' Use of Mobile Phone and Tablet Apps That Support Personal Management of Their Chronic or Long-Term Physical Conditions. *Journal of medical Internet research*. 2015 Dec 23;17(12):e287. doi: 10.2196/jmir.5043. PMID: 26701961.

88. Charlier N, Zupancic N, Fieuws S, et al. Serious games for improving knowledge and self-management in young people with chronic conditions: a systematic review and meta-analysis. *Journal of the American Medical Informatics Association : JAMIA*. 2016 Jan;23(1):230-9. doi: 10.1093/jamia/ocv100. PMID: 26186934.
89. Sattoe JN, Bal MI, Roelofs PD, et al. Self-management interventions for young people with chronic conditions: A systematic overview. *Patient education and counseling*. 2015 Jun;98(6):704-15. doi: 10.1016/j.pec.2015.03.004. PMID: 25819373.
90. Kleinpell R, Zimmerman J, Vermoch KL, et al. Promoting Family Engagement in the ICU: Experience From a National Collaborative of 63 ICUs. *Critical care medicine*. 2019 Dec;47(12):1692-8. doi: 10.1097/ccm.0000000000004009. PMID: 31567354.
91. Lancaster K, Abuzour A, Khaira M, et al. The Use and Effects of Electronic Health Tools for Patient Self-Monitoring and Reporting of Outcomes Following Medication Use: Systematic Review. *Journal of medical Internet research*. 2018 Dec 18;20(12):e294. doi: 10.2196/jmir.9284. PMID: 30563822.
92. Lycett HJ, Raebel EM, Wildman EK, et al. Theory-Based Digital Interventions to Improve Asthma Self-Management Outcomes: Systematic Review. *Journal of medical Internet research*. 2018 Dec 12;20(12):e293. doi: 10.2196/jmir.9666. PMID: 30541741.
93. Kew KM, Cates CJ. Home telemonitoring and remote feedback between clinic visits for asthma. *The Cochrane database of systematic reviews*. 2016 Aug 3(8):Cd011714. doi: 10.1002/14651858.CD011714.pub2. PMID: 27486836.
94. Kew KM, Malik P, Aniruddhan K, et al. Shared decision-making for people with asthma. *The Cochrane database of systematic reviews*. 2017 Oct 3;10:Cd012330. doi: 10.1002/14651858.CD012330.pub2. PMID: 28972652.
95. Clayman ML, Bylund CL, Chewning B, et al. The Impact of Patient Participation in Health Decisions Within Medical Encounters: A Systematic Review. *Medical decision making : an international journal of the Society for Medical Decision Making*. 2016 May;36(4):427-52. doi: 10.1177/0272989x15613530. PMID: 26585293.
96. Niznik JD, He H, Kane-Gill SL. Impact of clinical pharmacist services delivered via telemedicine in the outpatient or ambulatory care setting: A systematic review. *Research in social & administrative pharmacy : RSAP*. 2018 Aug;14(8):707-17. doi: 10.1016/j.sapharm.2017.10.011. PMID: 29100941.
97. Hill B, Richardson B, Skouteris H. Do we know how to design effective health coaching interventions: a systematic review of the state of the literature. *American journal of health promotion : AJHP*. 2015 May-Jun;29(5):e158-68. doi: 10.4278/ajhp.130510-LIT-238. PMID: 24720388.
98. Pamungkas RA, Chamroonsawasdi K, Vatanasomboon P. A Systematic Review: Family Support Integrated with Diabetes Self-Management among Uncontrolled Type II Diabetes Mellitus Patients. *Behavioral sciences (Basel, Switzerland)*. 2017 Sep 15;7(3). doi: 10.3390/bs7030062. PMID: 28914815.
99. Graham CD, Gouick J, Krahe C, et al. A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. *Clinical psychology review*. 2016 Jun;46:46-58. doi: 10.1016/j.cpr.2016.04.009. PMID: 27176925.

100. Chi NC, Demiris G. A systematic review of telehealth tools and interventions to support family caregivers. *Journal of telemedicine and telecare*. 2015 Jan;21(1):37-44. doi: 10.1177/1357633x14562734. PMID: 25475220.
101. Barelo S, Triberti S, Graffigna G, et al. eHealth for Patient Engagement: A Systematic Review. *Frontiers in psychology*. 2015;6:2013. doi: 10.3389/fpsyg.2015.02013. PMID: 26779108.
102. Voruganti T, Grunfeld E, Makuwaza T, et al. Web-Based Tools for Text-Based Patient-Provider Communication in Chronic Conditions: Scoping Review. *Journal of medical Internet research*. 2017 Oct 27;19(10):e366. doi: 10.2196/jmir.7987. PMID: 29079552.
103. Winston K, Grendarova P, Rabi D. Video-based patient decision aids: A scoping review. *Patient education and counseling*. 2018 Apr;101(4):558-78. doi: 10.1016/j.pec.2017.10.009. PMID: 29102063.
104. Bashi N, Fatehi F, Fallah M, et al. Self-Management Education Through mHealth: Review of Strategies and Structures. *JMIR mHealth and uHealth*. 2018 Oct 19;6(10):e10771. doi: 10.2196/10771. PMID: 30341042.
105. Kruse CS, Argueta DA, Lopez L, et al. Patient and provider attitudes toward the use of patient portals for the management of chronic disease: a systematic review. *Journal of medical Internet research*. 2015 Feb 20;17(2):e40. doi: 10.2196/jmir.3703. PMID: 25707035.
106. Scholl I, LaRussa A, Hahlweg P, et al. Organizational- and system-level characteristics that influence implementation of shared decision-making and strategies to address them - a scoping review. *Implementation science : IS*. 2018 Mar 9;13(1):40. doi: 10.1186/s13012-018-0731-z. PMID: 29523167.
107. McBain H, Shipley M, Newman S. The impact of self-monitoring in chronic illness on healthcare utilisation: a systematic review of reviews. *BMC health services research*. 2015 Dec 18;15:565. doi: 10.1186/s12913-015-1221-5. PMID: 26684011.
108. Anderson RJ, Bloch S, Armstrong M, et al. Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. *Palliative medicine*. 2019 Sep;33(8):926-41. doi: 10.1177/0269216319852007. PMID: 31184529.
109. Legare F, Adekpedjou R, Stacey D, et al. Interventions for increasing the use of shared decision making by healthcare professionals. *The Cochrane database of systematic reviews*. 2018 Jul 19;7:Cd006732. doi: 10.1002/14651858.CD006732.pub4. PMID: 30025154.
110. Oldfield BJ, Harrison MA, Genao I, et al. Patient, Family, and Community Advisory Councils in Health Care and Research: a Systematic Review. *Journal of general internal medicine*. 2019 Jul;34(7):1292-303. doi: 10.1007/s11606-018-4565-9. PMID: 30051331.
111. McCarron TL, Moffat K, Wilkinson G, et al. Understanding patient engagement in health system decision-making: a co-designed scoping review. *Systematic reviews*. 2019 Apr 18;8(1):97. doi: 10.1186/s13643-019-0994-8. PMID: 30999950.
112. Bombard Y, Baker GR, Orlando E, et al. Engaging patients to improve quality of care: a systematic review. *Implementation science : IS*. 2018 Jul 26;13(1):98. doi: 10.1186/s13012-018-0784-z. PMID: 30045735.

113. Liang L, Cako A, Urquhart R, et al. Patient engagement in hospital health service planning and improvement: a scoping review. *BMJ open*. 2018 Jan 30;8(1):e018263. doi: 10.1136/bmjopen-2017-018263. PMID: 29382676.
114. Sharma AE, Knox M, Mleczko VL, et al. The impact of patient advisors on healthcare outcomes: a systematic review. *BMC health services research*. 2017 Oct 23;17(1):693. doi: 10.1186/s12913-017-2630-4. PMID: 29058625.
115. Iezzoni LI, Chang Y, Matulewicz H, et al. Health plan enrollees with disability informing primary care practices and providers about their quality of care: A randomized trial. *Disability and health journal*. 2018 Oct;11(4):537-44. doi: 10.1016/j.dhjo.2018.05.006. PMID: 30054227.
116. Unaka N, Statile A, Jerardi K, et al. Improving the Readability of Pediatric Hospital Medicine Discharge Instructions. *Journal of hospital medicine*. 2017 Jul;12(7):551-7. doi: 10.12788/jhm.2770. PMID: 28699944.
117. King C, Goldman A, Gampa V, et al. Strengthening the role of Community Health Representatives in the Navajo Nation. *BMC public health*. 2017 Apr 21;17(1):348. doi: 10.1186/s12889-017-4263-2. PMID: 28431541.
118. Chronic Diseases in America -National Center for Chronic Disease Prevention and Health Promotion. <https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm>.
119. Stenberg U, Haaland-Overby M, Fredriksen K, et al. A scoping review of the literature on benefits and challenges of participating in patient education programs aimed at promoting self-management for people living with chronic illness. *Patient education and counseling*. 2016 Nov;99(11):1759-71. doi: 10.1016/j.pec.2016.07.027. PMID: 27461944.
120. Totten AM, Womack DM, Eden KB, et al. AHRQ Comparative Effectiveness Technical Briefs. *Telehealth: Mapping the Evidence for Patient Outcomes From Systematic Reviews*. Rockville (MD): Agency for Healthcare Research and Quality (US); 2016.
121. Dounavi K, Tsoumani O. Mobile Health Applications in Weight Management: A Systematic Literature Review. *American journal of preventive medicine*. 2019 Jun;56(6):894-903. doi: 10.1016/j.amepre.2018.12.005. PMID: 31003801.
122. Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. *BMJ (Clinical research ed)*. 2007 Jul 7;335(7609):24-7. doi: 10.1136/bmj.39246.581169.80. PMID: 17615222.
123. Tang PC, Overhage JM, Chan AS, et al. Online disease management of diabetes: engaging and motivating patients online with enhanced resources-diabetes (EMPOWER-D), a randomized controlled trial. *Journal of the American Medical Informatics Association : JAMIA*. 2013 May 1;20(3):526-34. doi: 10.1136/amiajnl-2012-001263. PMID: 23171659.
124. About Learning Health Systems. Content last reviewed May 2019. Agency for Healthcare Research and Quality, Rockville, MD. . 2019. <https://www.ahrq.gov/learning-health-systems/about.html>.
125. A ROADMAP FOR Patient and Family Engagement in Healthcare- Practice and Research Practical strategies for advancing engagement in healthcare—starting today. <https://www.air.org/sites/default/files/Roadmap-Patient-Family-Engagement.pdf>.

126. 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. doi: 10.15171/ijhpm.2018.43. PMID: 30316241.