

Evidence-based Practice Center Technical Brief Protocol

Project Title: Strategies for Patient, Family and Caregiver Engagement

I. Background and Objectives

The widely applied Chronic Care Model emphasizes the need for both an "informed activated patient" and a "prepared and proactive team" to improve patient outcomes.^{1,2} Multiple studies have demonstrated that activated patients have better health outcomes and lower utilization of emergency health care services.³ Conversely, low levels of patient engagement in direct patient care is associated with significant, serious or life- threatening adverse events.⁴

Interventions, such as tailored coaching interventions that increased patient activation, have been associated with improved intermediate outcomes, including chronic disease self-management behavior and reduced health care utilization.⁵ Self-management education and support interventions have also improved outcomes and function among patients with single and multiple chronic diseases.⁶⁻¹²

Despite the proven benefits of patient engagement and activation, not all patients have the capacity to be engaged and 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, and people with disabilities. 14

Clinicians and healthcare systems have key roles in patient and family engagement, so many strategies target clinicians to improve the patient-provider relationship by improving communication skills and shared decision making techniques.¹⁵⁻¹⁹ Clinicians often use complicated medical jargon, limiting patients' understanding of their care.²⁰ Communication studies show that clinicians quickly interrupt patients, allowing less opportunity for listening to concerns and building rapport.²¹ Patients and families do not feel empowered to speak up about their questions or concerns in health care environments, with greater risks among marginalized patients and families, including those with limited English language proficiency.^{22, 23} Interventions that target patient-provider communication have improved patient satisfaction, as well as patient-centered health outcomes (e.g., resolution of depression, anxiety, pain, blood pressure and improvement in functional status).^{15-19, 24, 25}

Engagement at Organizational and Policy Level. Increasingly, health care systems are implementing strategies to engage patients, families, and caregivers to improve care delivery, efficiency, outcomes, and patient experience, and reduce health care costs.^{26, 27} Part of the motivation was the Patient Protection and

Affordable Care Act (2010), which tied Medicare reimbursements with scores on a patient experience survey. A 2016 survey of over 1450 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. Patient and family engagement strategies have been integrated into advanced primary care models, including Patient Centered Medical Homes and Comprehensive Primary Care. 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. An early review of patient and family engagement in health care design identified case studies which demonstrated effects on patients, changes to services available to patients, and changes in staff attitudes to patient engagement, but few studies examined clinical outcomes. A more recent review identified process improvements, but few studies examined clinical outcomes.

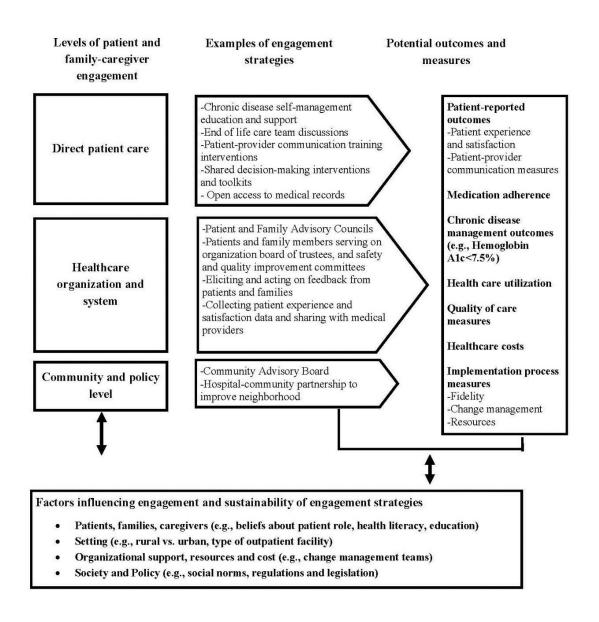
Objective of Technical Brief

The <u>objective of this technical brief</u> is to provide a framework and map of the currently available evidence on patient and family engagement strategies that have been used to help patients, families, and caregivers manage chronic conditions. The long-term goal is to inform decision making by health systems on which engagement strategies to deploy to improve outcomes. The Technical Brief will summarize the evidence on patient and family engagement, provide a conceptual or organizational framework to understand key components of the strategies and interventions of interest, highlight evidence for innovative strategies, describe barriers to implementation, and provide guidance regarding future research directions and priorities. To create a comprehensive profile of the evidence, we will systematically search for studies of the impact of engagement strategies on patient-reported outcomes (e.g., patient activation, patient experience/satisfaction, patient-provider communication, effectiveness of engagement), process outcomes (e.g., measures of chronic disease management and quality of care), health care system outcomes (e.g., utilization of hospital, emergency room, and primary care services), and clinical outcomes (e.g., disease-specific morbidity and mortality).

We will synthesize the published and grey literature into an evidence map that will include: 1) description of available systematic reviews and primary studies, 2) identification of areas where a new systematic review may help to synthesize the evidence in greater depth, and 3) demonstration of evidence gaps requiring additional primary research. To meet these aims, we will build on and adapt a conceptual framework on patient and family engagement interventions from Carman et al.³⁷ to categorize patient and

family engagement strategies into direct patient care level, health system or organizational level, and community/policy level interventions (**Figure 1**). Further, we will apply the definition of patient and family engagement from the 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 policy making — to improve health and health care."³⁷

Figure 1. Patient, family and caregiver engagement framework



II. Guiding Questions

We will use these questions to guide our work:

- 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?

III. Methods

The Technical Brief will integrate discussions with key informants with searches of the published literature and grey literature to inform the above Guiding Questions.

1. Data Collection

A. Discussions with Key Informants

To guide the project and the refinement of the Framework (Figure 1), we will first conduct discussions with approved key informants. We will seek their input on the guiding questions and the framework we plan to use.

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 will ask key informants to give input on what to emphasize in the methodologic

Table 1. Discussion Guide with key informants

Prior to the call key informants receive this information to guide the call:

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

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

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

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

Call 2: Word Cloud Brainstorm - 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, lack of evidence of what works best)

approach to the technical brief
(e.g. strategies, methods,
outcomes and what is most
important from each of their
perspectives (see **Table 1** for
key informant questions). We will
conduct conference calls in small
groups. We will adhere to Office
of Management and Budget
requirements to avoid using
survey methods with more than 9
participants. We will use a semistructured approach to engage key
informants. They will first be

provided information about the project and its goals. We will then elicit their perspectives on topics that pertain to patient and family engagement and the Guiding Questions described above. Sample topics to be discussed with the key informants are listed in **Table 1**. These questions will be used as a starting point for discussion. We may explore additional areas depending on the direction of the discussion and the key informant responses. The feedback from the key informants will be integrated with the expertise of our project team to guide and focus our review of the published and unpublished literature.

B. Published Literature Search

We will develop PubMed and CINAHL searches using a Boolean combination of search strings and terms for patient/consumer/caregiver/family engagement (i.e. "Population" terms) combined with terms for patient, family and caregiver engagement interventions (Table 2).

Our preliminary search indicated that we will need to sift through thousands of articles to identify three that meet our eligibility criteria. To keep the project manageable with the assigned time frame, we plan to use a step-wise approach:

- 1. Identification of systematic reviews from 2015 to the present;
- 2. Identification of original articles from 2015 to the present that were not captured in the included systematic reviews; and
- 3. Sampling (20%) of original articles from 2012 to 2015 to assess the proportion included or

missed in the systematic reviews in step 1

For the systematic review search, we will use the Cochrane validated search string for systematic reviews to search for high quality systematic reviews that can help to identify and characterize relevant studies in an efficient manner. We plan to focus attention initially on high quality systematic reviews (i.e., meeting standards set by the Institute of Medicine³⁸) published since 2015, including systematic reviews of randomized controlled trials (RCTs) and/or observational studies with comparison groups. We will use those reviews to extract as much information as possible regarding the Guiding Questions.

In step 2, we will augment the systematic review search by searching for and reviewing eligible original studies that describe patient, family and caregiver engagement models in all settings. In the search for original studies, we will start by looking for studies published since January 2015 that were not included in the systematic reviews we find. We will look for studies with a comparison group in each of the intervention categories (Figure 1). For implementation outcomes, we will include reviews that report on implementation (e.g. barriers, facilitators, resources, costs, change management) from studies without a comparison group. We will include studies that use quantitative or qualitative methods to assess outcomes. For the third step, we will perform a search of original articles published between 2012-2014 to estimate the extent to which systematic reviews have captured all relevant studies published before 2015, using at a 20% sample to estimate the number of eligible studies not captured by the systematic reviews. We will examine the characteristics of those studies to determine why they were not included in the systematic reviews, and then decide whether additional searching of the articles beyond the screened sample is needed to fill in gaps in the evidence map. We will use PubMed and CINAHL, and review reference lists in eligible studies.

Table 2. PubMed Database Search Strings

#	String	Yield
1.	Patient Participation[Mesh] OR "patient participation"[tiab] OR "patient	33927
Population	engagement" [tiab] OR "patient involvement" [tiab] OR "patient empowerment" [tiab] OR "patient partnership" [tiab] OR "patient activation" [tiab] OR "patient-activated" [tiab] OR "family participation"[tiab] OR "family engagement" [tiab] OR "family involvement" [tiab] OR "family empowerment" [tiab] OR "family partnership" [tiab] OR "family activation" [tiab] OR "consumer participation"[tiab] OR "consumer engagement" [tiab] OR "consumer involvement" [tiab] OR "consumer activation" [tiab] OR "consumer partnership" [tiab] OR "consumer activation" [tiab] OR "caregiver participation"[tiab] OR "caregiver engagement" [tiab] OR "caregiver involvement" [tiab] OR "caregiver empowerment" [tiab] OR "caregiver activation" [tiab] OR "patient context" [tiab] OR "patient capacity" [tiab] OR "patients capacity" [tiab]	
2.	Advisory Committees [Mesh] OR PFAC [tiab] OR "patient council" [tiab] OR	978913
Intervention	l lance case the freeze is the contract of the	
	"consumer council" [tiab] OR "family advisor" [tiab] OR "advisory council" [tiab]	
	OR "community advisory" [tiab] OR Self-Management [mh] OR "Self-	

#	String	Yield
	Management" [tiab] OR "Self Management" [tiab] OR Shared Decision Making	
	[mh] OR "decision making" [tiab] OR "decision-making" [tiab] OR "Speaking up" [tiab] OR telemedicine [mh] OR Electronic Health Records [mh] OR "Electronic Health Records" [tiab] OR "Medical Informatics" [mh] OR "health informatics" [tiab] OR "mobile health" [tiab] OR "eHealth" [tiab] OR "digital	
	health"[tiab] OR "smart phone"[tiab] OR "mobile app"[tiab] OR "mobile	
	applications"[tiab] OR "mHealth"[tiab] OR "smartphones" [tiab] OR Patient	
	Portals [mh] OR "Patient Portals" [tiab] OR Patient Access to Records [mh] OR "Patient	
	"Patient Access to Records" [tiab] OR "Opennotes" [tiab] OR Health Literacy [mh] OR literacy [tiab] OR hospice [tiab] OR palliative [tiab] OR "end-of-life" [tiab] OR	
	"end of life"[tiab] OR terminal care [mh] OR Palliative Care [mh] OR "patient	
	safety"[tiab] OR "decision support"[tiab] OR Advance Care Planning [mh] OR	
	"Advance Care Planning" [tiab] OR "Advance Directives" [tiab] OR "peer	
	support"[tiab] OR "social support"[tiab] OR "family support"[tiab] OR "healthcare	
	professional support" [tiab] OR "patient navigator" [tiab] OR Accountable Care	
	Organizations[mh] OR Population Health Management [MH] OR "Accountable	
	Care Organizations"[tiab] OR "Population Health Management" [tiab]	
1 AND 2	((Patient Participation[Mesh] OR "patient participation"[tiab] OR "patient	14286
-	engagement" [tiab] OR "patient involvement" [tiab] OR "patient empowerment"	
	[tiab] OR "patient partnership" [tiab] OR "patient activation" [tiab] OR "patient-	
	activated" [tiab] OR "family participation" [tiab] OR "family engagement" [tiab] OR	
	"family involvement" [tiab] OR "family empowerment" [tiab] OR "family	
	partnership" [tiab] OR "family activation" [tiab] OR "consumer participation" [tiab]	
	OR "consumer engagement" [tiab] OR "consumer involvement" [tiab] OR	
	"consumer empowerment" [tiab] OR "consumer partnership" [tiab] OR	
	"consumer activation" [tiab] OR "caregiver participation" [tiab] OR "caregiver	
	engagement" [tiab] OR "caregiver involvement" [tiab] OR "caregiver	
	empowerment" [tiab] OR "caregiver activation" [tiab] OR "patient context" [tiab]	
	OR "patient capacity" [tiab] OR "patients capacity" [tiab])) AND (Advisory	
	Committees [Mesh] OR PFAC [tiab] OR "patient council" [tiab] OR "patient	
	committee"[tiab] OR "patient advisor" [tiab] OR "family council" [tiab] OR	
	"consumer council" [tiab] OR "family advisor" [tiab] OR "advisory council" [tiab]	
	OR "community advisory" [tiab] OR Self-Management [mh] OR "Self-	
	Management" [tiab] OR "Self Management" [tiab] OR Shared Decision Making	
	[mh] OR "decision making" [tiab] OR "decision-making" [tiab] OR "Speaking up"	
	[tiab] OR telemedicine [mh] OR Electronic Health Records [mh] OR "Electronic	
	Health Records" [tiab] OR "Medical Informatics"[mh] OR "health	
	informatics"[tiab] OR "mobile health" [tiab] OR "eHealth" [tiab] OR "digital	
	health"[tiab] OR "smart phone"[tiab] OR "mobile app"[tiab] OR "mobile applications"[tiab] OR "mHealth"[tiab] OR "smartphones" [tiab] OR Patient	
	Portals [mh] OR "Patient Portals" [tiab] OR Patient Access to Records [mh] OR	
	"Patient Access to Records" [tiab] OR "Opennotes" [tiab] OR Health Literacy [mh]	
	OR literacy [tiab] OR hospice [tiab] OR palliative [tiab] OR "end-of-life" [tiab] OR	
	"end of life"[tiab] OR terminal care [mh] OR Palliative Care [mh] OR "patient	
	safety"[tiab] OR "decision support"[tiab] OR Advance Care Planning [mh] OR	
	"Advance Care Planning" [tiab] OR "Advance Directives" [tiab] OR "peer	
	support"[tiab] OR "social support"[tiab] OR "family support"[tiab] OR "healthcare	
	professional support" [tiab] OR "patient navigator" [tiab] OR Accountable Care	
	Organizations[mh] OR Population Health Management [MH] OR "Accountable	
	Care Organizations"[tiab] OR "Population Health Management" [tiab])	
4. Limit	Filters activated: Publication date from 2015/01/01 to 2019/12/31	4902
2015 -		
present		

#	String	Yield
5. Limit to	#4 AND Cochrane validated systematic review search	388
systematic		
reviews		
6. Original articles without systematic reviews	#4 AND without Cochrane validated systematic review search	4514

C. Grey Literature Search

We will design a 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 will target the gray literature search on reports from national organizations, including the Patient Centered Outcomes Research Institute (PCORI), and the Institute for Patient- and Family-Centered Care, Institute for Healthcare Improvement, and governmental agencies such as AHRQ and the National Institute of Nursing Research. We also will solicit information on other resources, programs, and organizations from our key informants.

D. Process for Selection of Studies

All titles and abstracts identified through searches will be independently reviewed by two trained team members for eligibility against our inclusion/exclusion criteria organized by PICOTS (population, intervention, comparator, outcome, timing, study design) (Table 3). Studies marked for possible inclusion by any reviewer will undergo a full-text review. For abstracts without adequate information to determine eligibility, we will retrieve the full text and then make the determination. All results will be tracked in an EndNote® database (Thomson Reuters, New York, NY). Each full-text article will be independently reviewed by two trained members of the research team for inclusion or exclusion on the basis of the eligibility criteria. If the reviewers disagree, conflicts will be resolved by discussion and consensus or by consulting another member of the review team. Results of the full text review will also be tracked in the EndNote® database, including the reason for exclusion when they did not meet the eligibility criteria.

 Table 3. Draft Inclusion and Exclusion Criteria for Guiding Questions

PICOT	Include	Exclude
Population	 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 Ethnic and racial minority Limited language skills Low literacy/low health literacy 	None

PICOT	Include	Exclude	
	Cognitive impairment		
Interventions	Direct patient level interventions, including: Medical home/team based care Educational resources, particularly to improve chronic disease self-management Self-management programs Shared decision making (e.g., palliative or end of life or treatment decision making) Practice, health system, and reimbursement interventions, including: OpenNotes Mobile Apps Patient and Family Advisory Councils Models under alternative payment mechanisms Community level interventions, including: Caregiver support Peer support Social support (rides to physician office, food banks) Include strategies that engage patients, caregivers and families on Level 3 and above of the Healthcare Information and Management Systems Society: HIMSS patient engagement framework. ³⁹	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 Healthcare Information and Management Systems Society: HIMSS patient engagement framework. ³⁹	
Comparators	Any comparator (pre/post, concurrent) Note: For reviews addressing implementation of engagement strategies, we will not require a comparison group	No comparison group	
Outcomes	Intermediate outcomes	None	
Timing	All timing Right after implementation strategy (within 3 months) Longer follow up (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	

disease, US-United States

2. Data Organization and Presentation

A. Information Management and Data Abstraction

We will abstract information guided by our conceptual framework, including intervention type and description (which could include multiple components). We plan to apply a "ladder" to characterize intensity of engagement, based on a recent review focused on patient and family engagement strategies to improve medication safety. We will abstract information about the population (e.g., characteristics of patients/conditions [age, race/ethnicity, sex, socioeconomic factors, vulnerable patients, health literacy], setting, characteristics of the providers and health system [e.g., outpatient, hospital, geographic setting], types of measures/outcomes, resource intensiveness, and description of provisions for sustainability). For abstraction from systematic reviews, we will abstract year of publication, purpose of the review, search dates and databases searched, number of studies included, populations and settings in the studies, engagement intervention characteristics, type of studies included, how study quality was rated, methods of synthesis, number of patients included, main findings (including harms), limitations, and applicability. Table 4 shows the proposed data abstraction elements.

Table 4. Proposed Data Elements to be Abstracted into Evidence Tables for Each Study

Data Element	Details
Study characteristics	Study design Inclusion/exclusion criteria
Population characteristics	Age (mean, range) Race (percentages) Chronic diseases Vulnerable patients (e.g., end of life, minority, low income)
Intervention characteristics	Description of patient and family engagement strategy Level of intervention (see Figure 1 for categories) Intervention components
Comparator	Comparator (s)
Outcomes examined	Types of outcomes examined in the study Summary of main findings Barriers and Facilitators to Implementation
Timing/duration	Timing of outcome measurement (follow-up)
Setting	Setting of where implemented and evaluated- outpatient, hospital, community Geographic location Rural/urban

B. Data synthesis and presentation.

We plan to use a mix of methods for summarizing and displaying the types of evidence available on the topic, including evidence tables, bar graphs, flow charts, and bubble plots, all guided by the organizing framework shown in **Figure 1**. For example, for Guiding Question 1A, an evidence table will display summary information about characteristics of patients with a separate row for each type of intervention, and a separate column for each type of patient characteristic. Bar graphs (or pie charts) will highlight the distribution of evidence according to selected characteristics of studies, such as year of publication. A flow chart will show how studies can be sorted into related subsets of evidence. To create a summary map of evidence, we will use figures, such as a bubble plot, to show how the number or collective size of studies varies within a given subset, using different shading or symbols to denote distinguishing features of studies and interventions. These displays of evidence will help to reveal where evidence is most abundant and where it is missing, and help to clarify where additional research is needed and where a new SR would be helpful.

In the text, we will describe barriers and facilitators to implementation. We will describe current published evidence as identified in our review, as well as highlights from the grey literature, for innovative published patient and family engagement strategies.

IV. References

- 1. Von Korff M, Gruman J, Schaefer J, et al. Collaborative management of chronic illness. Ann Intern Med. 1997 Dec 15;127(12):1097-102. PMID: 9412313.
- 2. Wagner EH, Bennett SM, Austin BT, et al. Finding common ground: patient-centeredness and evidence-based chronic illness care. J Altern Complement Med. 2005;11 Suppl 1:S7-15. doi: 10.1089/acm.2005.11.s-

- 7. PMID: 16332190.
- 3. Remmers C, Hibbard J, Mosen DM, et al. Is patient activation associated with future health outcomes and healthcare utilization among patients with diabetes? J Ambul Care Manage. 2009 Oct-Dec;32(4):320-7. doi: 10.1097/JAC.0b013e3181ba6e77. PMID: 19888008.
- 4. Weingart SN, Zhu J, Chiappetta L, et al. Hospitalized patients' participation and its impact on quality of care and patient safety. Int J Qual Health Care. 2011 Jun;23(3):269-77. doi: 10.1093/intqhc/mzr002. PMID: 21307118.
- 5. Hibbard JH, Greene J, Tusler M. Improving the outcomes of disease management by tailoring care to the patient's level of activation. Am J Manag Care. 2009 Jun;15(6):353-60. PMID: 19514801.
- 6. Fitzpatrick SL, Schumann KP, Hill-Briggs F. Problem solving interventions for diabetes self-management and control: a systematic review of the literature. Diabetes Res Clin Pract. 2013 May;100(2):145-61. doi: 10.1016/j.diabres.2012.12.016. PMID: 23312614.
- 7. 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.
- 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. Med Care. 1999 Jan;37(1):5-14. 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. J Gen Intern Med. 1988 Sep-Oct;3(5):448-57. doi: 10.1007/bf02595921. PMID: 3049968.
- 10. Rost K, Nutting P, Smith JL, et al. Managing depression as a chronic disease: a randomised trial of ongoing treatment in primary care. Bmj. 2002 Oct 26;325(7370):934. doi: 10.1136/bmj.325.7370.934. PMID: 12399343.
- 11. Bayliss EA, Ellis JL, Steiner JF. Barriers to self-management and quality-of-life outcomes in seniors with multimorbidities. Ann Fam Med. 2007 Sep-Oct;5(5):395-402. doi: 10.1370/afm.722. PMID: 17893380.
- 12. Effing T, Monninkhof EM, van der Valk PD, et al. Self-management education for patients with chronic obstructive pulmonary disease. Cochrane Database Syst Rev. 2007 Oct 17(4):Cd002990. doi: 10.1002/14651858.CD002990.pub2. PMID: 17943778.
- 13. 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.
- 14. Conway JJ, B.; Edgman-Levitan, S.; Schlucter, J.; Ford, D.; Sodomka, .P; Simmons, L. 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.
- http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.100.9620&rep=rep1&type=pdf
- 15. 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. Ann Fam Med. 2004 Nov-Dec;2(6):595-608. doi: 10.1370/afm.142. PMID: 15576546.
- 16. Peat M, Entwistle V, Hall J, et al. Scoping review and approach to appraisal of interventions intended to involve patients in patient safety. J Health Serv Res Policy. 2010 Jan;15 Suppl 1:17-25. doi: 10.1258/jhsrp.2009.009040. PMID: 20075123.
- 17. Entwistle VA, McCaughan D, Watt IS, et al. Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. Qual Saf Health Care. 2010 Dec;19(6):e33. doi: 10.1136/qshc.2009.039743. PMID: 21127092.
- 18. Kaplan SH, Greenfield S, Ware JE, Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Med Care. 1989 Mar;27(3 Suppl):S110-27. PMID: 2646486.
- 19. Schillinger D, Piette J, Grumbach K, et al. Closing the loop: physician communication with diabetic

- patients who have low health literacy. Arch Intern Med. 2003 Jan 13;163(1):83-90. PMID: 12523921.
- 20. Castro CM, Wilson C, Wang F, et al. Babel babble: physicians' use of unclarified medical jargon with patients. Am J Health Behav. 2007 Sep-Oct;31 Suppl 1:S85-95. doi: 10.5555/ajhb.2007.31.supp.S85. PMID: 17931142.
- 21. Marvel MK, Epstein RM, Flowers K, et al. Soliciting the patient's agenda: have we improved? Jama. 1999 Jan 20;281(3):283-7. PMID: 9918487.
- 22. Wilson E, Chen AH, Grumbach K, et al. Effects of limited English proficiency and physician language on health care comprehension. J Gen Intern Med. 2005 Sep;20(9):800-6. doi: 10.1111/j.1525-1497.2005.0174.x. PMID: 16117746.
- 23. 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.
- 24. Cooper LA, Roter DL, Carson KA, et al. A randomized trial to improve patient-centered care and hypertension control in underserved primary care patients. J Gen Intern Med. 2011 Nov;26(11):1297-304. doi: 10.1007/s11606-011-1794-6. PMID: 21732195.
- 25. 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. Med Care. 2007 Apr;45(4):340-9. doi: 10.1097/01.mlr.0000254516.04961.d5. PMID: 17496718.
- 26. Herrin J, Harris KG, Kenward K, et al. Patient and family engagement: a survey of US hospital practices. BMJ Qual Saf. 2016 Mar;25(3):182-9. doi: 10.1136/bmjqs-2015-004006. PMID: 26082560.
- 27. Nickel WK, Weinberger SE, Guze PA. Principles for Patient and Family Partnership in Care: An American College of Physicians Position Paper. Ann Intern Med. 2018 Dec 4;169(11):796-9. doi: 10.7326/m18-0018. PMID: 30476985.
- 28. Millenson MLM, J. Will the Affordable Care Act Move Patient-Centeredness to Center Stage? 2012. https://www.urban.org/sites/default/files/publication/25191/412525-Summary-Will-the-Affordable-Care-Act-Move-Patient-Centeredness-to-Center-Stage-.PDF
- 29. Comprehensive Primary Care Initiative. 2019. https://innovation.cms.gov/initiatives/comprehensive-primary-care-initiative/. Accessed on 21 June 2019.
- 30. PCMH Standards and Guidelines (2017 Edition, Version 2). 2017. https://www.kentuckyrec.com/wp-content/uploads/2017/10/02.-PCMH-Standards-and-Guidelines-2017-Edition-Version-2-9-30-17.pdf
- 31. Working With Patient and Families as Advisors: Implementation Handbook. 2008.
- https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy 1/Strat1_Implement_Hndbook_508_v2.pdf
- 32. Creating a Patient and Family Advisory Council: A Toolkit for Pediatric Practices. 2012. https://www.nichq.org/sites/default/files/resource-file/PFAC%20Toolkit.pdf
- 33. Key Steps for Creating Patient and Family Advisory Councils in CPC Practices. 2013. https://innovation.cms.gov/Files/x/cpci-patientfamengresource.pdf
- 34. Moving Forward with Patient- and Family-Centered Care: Partnerships for Quality and Safety. 2019. http://www.ipfcc.org/events/seminars.html.
- 35. Crawford MJ, Rutter D, Manley C, et al. Systematic review of involving patients in the planning and development of health care. Bmj. 2002 Nov 30;325(7375):1263. doi: 10.1136/bmj.325.7375.1263. PMID: 12458240.
- 36. Johnson KE, Mroz TM, Abraham M, et al. Promoting Patient and Family Partnerships in Ambulatory Care Improvement: A Narrative Review and Focus Group Findings. Adv Ther. 2016 Aug;33(8):1417-39. doi: 10.1007/s12325-016-0364-z. PMID: 27352378.
- 37. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health Aff (Millwood). 2013 Feb;32(2):223-31.

doi: 10.1377/hlthaff.2012.1133. PMID: 23381514.

- 38. Institute of Medicine (US) Committee on Standards for Systematic Reviews of Comparative Effectiveness Research; Eden J, Levit L, Berg A, Morton S, editors. Finding What Works in Health Care: Standards for Systematic Reviews. Washington, (DC): National Academies Press (US); 2011. PubMed PMID: 24983062.
- 39. (HIMSS) HIaMSS. Patient Engagement Framework. Chicago, IL; 2014 [updated 2017].
- ^{40.} Kim JM, Suarez-Cuervo C, Berger Z, et al. Evaluation of Patient and Family Engagement Strategies to Improve Medication Safety. Patient. 2018 Apr;11(2):193-206. doi: 10.1007/s40271-017-0270-8. PMID: 28795338.

V. Definition of Terms

Patient engagement: Continuum from "basic participation," in which patients answer providers' questions, to "engagement," in which patients take an active role by asking questions, to "activation," in which patients critically examine problems and problem solve, to "empowerment," in which patients take control and make their own choices.

VI. Summary of Protocol Amendments

None.

VII. Key Informants

Within the Technical Brief process, key informants serve as a resource to offer insight into the clinical context of the technology/intervention, how it works, how it is currently used or might be used, and which features may be important from a patient of policy standpoint. They may include clinical experts, patients, manufacturers, researchers, payers, or other perspectives, depending on the technology/intervention in question. Differing viewpoints are expected, and all statements are crosschecked against available literature and statements from other Key informants. Information gained from Key informant interviews is identified as such in the report. Key informants do not do analysis of any kind nor contribute to the writing of the report and have not reviewed the report, except as given the opportunity to do so through the public review mechanism.

Key informants must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals are invited to serve as Key informants and those who present with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential conflicts of interest identified.

VIII. Peer Reviewers

Peer reviewers are invited to provide written comments on the draft report based on their clinical, content, or methodologic expertise. Peer review comments on the preliminary draft of the report are considered by the EPC in preparation of the final draft of the report. Peer reviewers do not participate in writing or editing of the final report or other products. The synthesis of the scientific literature presented in the final report does not necessarily represent the views of individual reviewers. The dispositions of the peer review comments are documented and will be published three months after the publication of the Technical Brief. Potential reviewers must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional

conflicts of interest. Invited peer reviewers may not have any financial conflict of interest greater than \$10,000. Peer reviewers who disclose potential business or professional conflicts of interest may submit comments on draft reports through the public comment mechanism.

IX. EPC Team Disclosures

EPC core team members must disclose any financial conflicts of interest greater than \$1,000 and any other relevant business or professional conflicts of interest. Related financial conflicts of interest that cumulatively total greater than \$1,000 will usually disqualify EPC core team investigators.

X. Role of the Funder

This project was funded under Contract No. HHSA290201500006I from the Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services. The Task Order Officer reviewed contract deliverables for adherence to contract requirements and quality. The authors of this report are responsible for its content. Statements in the report should not be construed as endorsement by the Agency for Healthcare Research and Quality or the U.S. Department of Health and Human Services.